A conceptual model of the risk of elder abuse posed by incontinence and care dependence

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Aims and objectives: To describe and critically analyse the thinking that led to the concept of an association between incontinence, care dependence and elder abuse.

Background: Coercive or abusive continence care practices include chastising a person for their incontinence and overriding their attempts to resist continence care. Neglect in continence care is characterised by withholding or delaying responding to requests for help to maintain continence or to manage incontinence, and restricting a person’s access to toileting assistance, incontinence aids or hygiene care.

Methods: Contemporary biomedical understandings about incontinence and influencing concepts from the fields of sociology, psychology and nursing were analysed to inform the design of a conceptual model that elucidates possible associations between incontinence, care dependence and elder abuse.

Results: Ideas generated from an analysis of the concepts led to the development of a model termed the “Model of Attributes to Abuse of Dependent Elders in Continence Care” (MADE-CC). The MADE-CC theorises factors that cause and contribute to abuse in continence care. Carer factors include physical and emotional exhaustion, frustration related to the inability to control or predict incontinence, resentment associated with constraints imposed by care dependence, disgust associated with physical contact with urine/faeces, limited knowledge and skills about incontinence and ethical conflicts concerning care. Care recipient factors include frequent and severe incontinence, cognitive impairment and a history of physical or psychological trauma. Social factors that are theorised include the stigmatised nature of incontinence, social taboos and cultural norms and the private nature of continence care.

Conclusions: The MADE-CC illuminates the potential risk of elder abuse posed by incontinence and care dependence. It should be used to improve ethical care of older people and stimulate debate about everyday ethics in the care of older people who are care dependent and to optimise their participation in decisions about their health and well-being.

Implications for practice: Nurses and carers should be aware of the multiple interrelated factors that contribute to the risk of elder abuse in the caregiving encounter, including the role of emotions.

KEYWORDS

care dependence, caregiving, carers, elder abuse, incontinence, nursing homes
1 | BACKGROUND

Elder abuse is a disturbing, underreported and highly emotional issue that elicits public outrage, blame, recrimination and calls for stronger regulation and surveillance. The Toronto Declaration (2002) defines elder abuse as "a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person." The World Health Organization (WHO) (2002) identifies five types of elder abuse: (i) physical, (ii) psychological or emotional, (iii) sexual, (iv) financial and (v) intentional or unintentional forms of neglect. For the purpose of this study, the term "elder abuse" will be used as the all-inclusive term.

Multiple complex interactions at individual, relationship, community and societal levels place an older person at risk of abuse. These factors include, but are not limited to dementia (Hansberry, Chen, & Gorbien, 2005), disabilities (Ansello & O'Neill, 2010) and chronic health problems (Lowenstein, Eiskovits, Band-Winterstein, & Enos, 2009), low social support, loneliness, social isolation and lack of social networks (Acero et al., 2010; Dong, Beck, & Simon, 2009). The quality of the relationship between the older person and the perpetrator is another important factor, as is intergenerational violence (Biggs, Manthorpe, Tinker, Doyle, & Erens, 2009; Yan & Tang, 2003). In institutions and healthcare settings, risk factors include, but are not limited to inadequate staff training and supervision, inadequate staff to carry out daily activities and ageist attitudes (Jogest, Daly, & Hartz, 2008; Phillips & Guo, 2011).

One factor that warrants further attention is the risk posed by urinary and/or faecal incontinence (UI) and care dependence. Urinary incontinence (UI) affects between 25% and 45% of the general population, affecting more women than men by a ratio of 2:1. Similarly, FI affects between 11% and 15% of the general population (Milsom et al., 2017). Both UI and FI disproportionately affect older people who are care dependent (Wagg et al., 2017). In part, this increased risk is due to cognitive and/or mobility impairments associated with neurological conditions such as dementia, stroke, Parkinson’s Disease or Multiple Sclerosis (Wagg et al., 2017). Incontinence is a frequent problem in mid-to late-stage dementia, and the risk increases as the disease progresses (Drennan, Rait, Cole, Grant, & Iliffe, 2013; Apostolidis et al., 2017). Similarly, UI affects around 50% of people who experience a stroke in the acute phase, and up to 38% are still incontinent 1 year later (Williams, Silkanth, Bird, & Thrift, 2012). Likewise, 25% of women and 28% of men with Parkinson’s disease experience UI (Siegl, Lassen, & Saxer, 2013), as do up to 92% of people with Multiple Sclerosis (Khafaf et al., 2015).

Incontinence in older adults is costly to manage, a significant risk factor for falls, depression, social isolation, skin breakdown, admission to a nursing home or hospital, and is independently associated with mortality (Wagg et al., 2017). The aetiology of incontinence in older adults is multifaceted, and risk factors for UI and FI differ; however functional causes are common, that is the inability to reach and use the toilet due to cognitive and/or physical impairments (Wagg et al., 2017).

Caring for a person with UI and/or FI typically involves monitoring their continence status, pre-empting their incontinence, prompting or assisting the person to go to the toilet, bathing or showering the person after an episode of incontinence, applying, checking and changing their incontinence products, washing wet or soiled clothes and bedding and cleaning the physical environment. Based on qualitative interviews with nurses and formal carers working in nursing homes, daily and night field observations in two nursing homes (Ostaszkiewicz, 2013) and a review of empirical and theoretical literature, the author proposes an association between incontinence, continence caregiving and the following forms of elder abuse: physical abuse, psychological/ emotional abuse and/or neglect. This abuse may take the form of coercion, verbal chastisement and/or neglect.

Coercive continence care practices include the use of verbal or physical force to wash a person, to accept wearing incontinence pads or other forms of incontinence containment and to accept continence checks. The underlying intent is to ensure a care recipient is clean and to protect them from visible incontinence, that is to ensure their incontinence is concealed and concealed.

Chastising a person for being incontinent involves admonishing them and arguably represents a form of verbal abuse. It causes embarrassment and shame. According to early anthropological research, embarrassment and shame are powerful emotions that are
often used as means of social control (Benedict, 1959). The anticipation or experience of being chastised or admonished for being incontinent is likely to function as a powerful form of social conditioning that affects how individuals respond to attempts to assist them with their incontinence. It is also possible that some carers use chastisement because this is how they learnt to communicate about incontinence in early childhood. Muller-Hergl (2004) claimed the caregiving encounter may be affected by the possibility that providing continence care and receiving continence care may rekindle communication and behavioural strategies learnt in early childhood during toilet training.

Neglect in continence care is characterised by withholding or delaying responding to a care-dependent person’s request for continence care and/or restricting their access to toileting assistance, incontinence aids or hygiene care. Attempts to restrict the number of incontinence products a care recipient uses to minimise organisational expenditure could be considered a form of neglect. So too, could the practice of deferring changing a person’s absorbent incontinence pad until it has reached maximum absorbency.

1.1 The conceptual framework for the model

Using the WHO classification and drawing on contemporary biomedical understandings about incontinence and influencing concepts from the fields of sociology, psychology and nursing, and her clinical practice knowledge, the author developed a model to conceptualise causal and contributing factors between incontinence, care dependence, and physical elder abuse, psychological/emotional elder abuse and/or elder neglect. The global literature in PubMed, MEDLINE, PsycINFO, BIOSIS, Science Direct and Cochrane Central was searched. Search terms included incontinence, care dependence, elder abuse, elder mistreatment, elder maltreatment, prevalence, incidence, risk factors, protective factors, outcomes and consequences.

The model titled the "Model of Attributes to Abuse of Dependent Elders in Continence Care" (MADE-CC) comprises carer factors, care recipient factors and social factors (Figure 1). Causal and contributing carer factors include:

1. Physical and emotional exhaustion
2. Frustration related to the inability to control or predict incontinence
3. Resentment related to constraints imposed by care dependence
4. Disgust associated with physical contact with urine and faeces
5. Limited knowledge and skills about incontinence
6. Ethical conflicts

Causal and contributing care recipient factors include:

1. Frequent and severe incontinence
2. Cognitive impairment
3. Rejection of care
4. A history of physical or psychological trauma

Causal and contributing social factors include:

1. The stigmatised nature of incontinence
2. Social taboos and cultural norms
3. The private nature of continence care
2 | CARER FACTORS

2.1 | Physical and emotional exhaustion

Physical and emotional exhaustion associated with the burden of care is a known risk factor for elder abuse by family carers (Johannesen & LoGiudice, 2013). Caregiving associated with incontinence is highly labour-intensive undertaking that can be physically and emotionally exhausting, particularly if the care recipient has both UI and FI (dual incontinence), or frequent and severe incontinence; and cognitive impairment with associated behavioural and psychological symptoms of dementia (BPSD).

According to the findings of a population-based survey of 4,010 respondents in Europe aged 65 years or older who were in need for help in home care, family carers of people with incontinence report higher levels of burden or stress than carers of people without incontinence (OR = 2.2, 95% CI 1.8–2.7) (Selbye et al., 2009). Part of the burden of caregiving associated with incontinence may relate to the care recipient's frequent need for assistance to use the toilet. Selbye et al. (2009) found 40% of their sample required help to use the toilet.

Qualitative research suggests the burden of caring for a person with incontinence is multifaceted. For example, in addition to coping with a change in their role and relationship (Cassells & Watt, 2003), family carers (i.e., spouses) describe having to deal with the stigma of incontinence (Tseng, Huang, Yu, & Lou, 2015). In an effort to minimise care recipients' incontinence and associated distress and to minimise their workload, some family carers become hypervigilant (Cassells & Watt, 2003; Tseng et al., 2015) and avoid taking a short break because of the risk that the care recipient could experience an episode of incontinence (Cassells & Watt, 2003). Similarly, Lobchuk and Rosenberg (2014) reported caring for a family member with incontinence was life changing, and the challenges of caregiving were compounded by having to deal with painful responses of others.

Incontinence causes considerable angst for family carers caring for a person with dementia at home and is a key factor in their management decisions (Drennan, Cole, & Illiffe, 2011). Depending on the severity of the care recipient's dementia, family carers may have to cope with the person's limited ability to recognise and respond to the urge to void or locate and use the toilet, difficulties performing toileting activities, limited ability to manage soiled or wet clothing, inappropriate voiding and resistance to toileting assistance. Despite the significance of these problems, most family carers do not seek health professionals help until the point of a crisis, as they wish to preserve the dignity and personhood of the person for whom they care (Drennan et al., 2011).

Although formal carers are also likely to care for people who have incontinence and associated complex behavioural symptoms that warrant attention, the physical and emotional impact is likely to be considerably less than for family carers. Unlike family carers, they spend considerably less time performing continence care activities and are not responsible for the care recipients' needs beyond their shift. Incontinence in nursing homes is typically managed with a combination of toileting assistance programmes and incontinence pads (Flanagan et al., 2012). A recent time and motion study of direct care activities in Australian residential aged care homes revealed personal carers spent approximately 45% of their time on direct care, corresponding to 3.5 hr in an 8-hr daytime shift. Each resident received an average of 30 min of direct care. The time involved in providing an episode of toileting assistance varied from 7 to 17 min, and the time involved in checking and changing residents' pads varied from 9 to 12 min (Qian et al., 2014). Thus, managing incontinence in an institutional context is not burdensome.

2.2 | Frustration related to the inability to control or predict incontinence

Qualitative research suggests that there is a "burden of care" associated with incontinence that is, in part, related to its unpredictability (Cassells & Watt, 2003; Gallagher & Pierce, 2002; Ostaszewicz, 2013). Although some people have predictable voiding patterns, others do not (Colling, Coudinder, Hadley, Eisch, & Campbell, 1992). One of the implications of this unpredictability is that carers need to remain constantly vigilant as previously stated. Another is that it places considerable restrictions on family carers and care recipients' abilities to socialise outside the home environment (Cassells & Watt, 2003). Social isolation is a known risk factor for elder abuse (Johannesen & LoGiudice, 2013). These factors collectively may be a source of considerable stress for family carers that set the scene for elder abuse.

Staff working in nursing homes also deal with unpredictability in their day-to-day work (Ostaszewicz, 2013), as do nurses working in acute care (Ebright, Patterson, Chalko, & Render, 2003). Incontinence is one many factors that contribute to the difficulty in controlling or predicting work, particularly when it is uncontained and uncontrolled. This situation occurs when a person fails to receive assistance to the toilet in a timely manner, or when the incontinence pads they are wearing are infrequently changed, or when a person with incontinence declines to wear an incontinence pad. As uncontained incontinence and other adverse unplanned issues can occur at any time, diverting them from responding to the task at hand, formal carers may feel frustrated about their work environment.

2.3 | Resentment associated with constraints imposed by care dependence

The author suggests that resentment associated with the constraints imposed by a care recipient's continence care needs may also increase the risk of elder abuse by family carers. There are multiple studies about the stress of caring for a family member. Collectively, these show these family carers experience depression, anxiety and stress as well as feelings of helplessness, hopelessness and resentment. In a sample of 417 family carers, Shaffer, Dooley, and Williamson (2007) reported an association between abuse and carers' feelings of resentment. Similarly, according to the findings of a study in which family carers were randomised to a 4-week psychoeducational group intervention or control group, the role of resentment among carers appears to be linked to carers' attributions regarding care recipients' actions (Martin-Cook, Remakel-Davis, Svettik, Hyman, & Weiner, 2003). Whilst care recipient behavioural disturbance was correlated...
with carer resentment and depression, the primary relationship was between behaviours perceived by the family carer as manipulative or willful and carer resentment and depression. Given the contractual nature of formal caregiving, formal carers are less likely to feel a sense of resentment associated with the care recipient's dependence than family carers.

2.4 Disgust associated with physical contact with urine and faeces

Another causal or contributing factor that may be associated with elder abuse is the emotion of disgust which is usually triggered by physical contact with a care recipient's urine and/or faeces. Sociological understanding about social norms and cultural symbols that surround the intimate part of the body indicate providing and receiving intimate care is identified as socially distasteful and faeces can be emotionally triggering for carers. (Isakson, 2000, 2002). Sociologist claim "disgust is rooted in fear of contamination, whether directly through oral incorporation or touching, or more remotely through visual images or moral pollution" (Twigg, 2000 p. 395). It typically evokes distancing and self-protective responses. The dilemma for carers who provide continence care is that they have no choice but to grapple with incontinence if caregiving is to be sustained.

Based on a reinterpretation of 105 relations between the elderly and their adult children, Isakson (2000, 2002) claimed family carers experienced a range of emotions associated with caregiving, including a sense of disgust about having to have physical contact with urine and faeces. This emotion was coupled with a sense of hurt when care recipients rejected or resisted their efforts to help them.

The emotion of disgust among formal carers is an under-researched topic and little is known about the strategies they employ to manage such feelings to perform their role. In one of the few studies available, nurses caring for patients with diarrhoea rated odour as one of the most unpleasant aspect of caregiving (Majid, Emery, & Whelan, 2008). In a theoretical discourse on disgust in nursing, Holmes, Perron, and O’Byrne (2006) claimed “the unclean side of nursing is rarely accounted for in academic literature: it is silenced” (p. 305). Interviews with nurses and formal carers in nursing homes in my own research suggest they view their work as socially tainted. For example, one staff member believed other people would be disgusted by her role because she had contact with some “unspeakable matter.” Other staff said, “we just do the dirty work.” Staff felt it was important to emotionally distance themselves from their feeling of disgust when handling residents’ urine or faeces or other bodily fluids. A staff member stated she had to “take herself [metaphorically] away from it [incontinence]” to deal with the disgust she felt from having to deal with a resident’s incontinence, as she attempted to perform her role (Ostaszkiewicz, O'Connell, & Dunning, 2016).

It is almost 60 years since the seminal researcher, Isobel Menzies (1960) claimed that nurses adopted a set of largely unsuccessful evasive or avoidance responses which was a response to their constant exposure to anxiety-providing situations such as having to carry out tasks which, by ordinary standards, are distasteful, disgusting, and frightening” (p. 98) and deal with people who are highly vulnerable, sometimes in pain, often anxious and alone, and who are facing death. Such situations are likely to evoke a mix of powerful and sometimes, contradictory emotions: compassion, pity, fear, disgust, envy, sexual desire. She also asserted nurses generally had no emotional support to deal with such situations and were socialised to maintain an almost inhuman self-control.

More recently, Bolton (2005), Jervis (2001), Twigg (2000) and Picco, Santoro & Garrino (2010) found professionals who work closely with the body employed distancing strategies to manage the stigma and taboo associated with the work they perform. Disgust is a culturally mediated, but powerful human emotion that has to be managed in the caregiving encounter. It is probable carers and care recipients are engaged in considerable emotional labour: concealing disgust and embarrassment: Indeed, for carers, it is important to project a caring approach (Dowling, 2006). Thus, the caregiving encounter may be characterised by repressed emotions and tensions. A theoretical study about how stigma affects social interactions suggests non-stigmatised individuals are engaged in a process of emotional labour so that they are not seen by other people as prejudiced towards the stigmatised person (Garca, Crocker, & Wyman, 2005). The researchers contend 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.

2.5 Limited knowledge and skills about incontinence

Historically, incontinence was viewed as a behavioural and psychological disorder, rather than a symptom caused by urological, gynaecological or neurological disorders. Therefore, past treatments were largely punitive (Ostaszkiewicz, 2016). As previously suggested, if carers (formal or family) interpret the person’s incontinence or associated efforts to self-manage and conceal the problem as a behavioural act or believe the person is voluntarily incontinent to gain attention, it is possible that care encounters will be characterised by considerable tension and lead to punitive care.

The International Consultation on Incontinence (ICI) (Newman et al., 2017) identifies gaps in the general public’s knowledge about the causes of incontinence, its prevention, treatment and management. The belief that incontinence is a normal part of ageing or a normal part of being a woman is widespread. There is also a lack of information about how to access services, which is a major barrier to help seeking.

There are also significant gaps in nurses’ and nursing assistants’ knowledge about incontinence and its management. Freundl and Dugas (1992) explored the relationships between attitudes, knowledge and institutional culture relative to the management of UI in the older adult in a purposive sample of 92 Registered Nurses, 62 Licensed Practice Nurses, 191 Nursing Assistants from 16 different extended-care agencies in the US and found a mean knowledge correct score of 56%. Only, 57% of respondents recognised as false a statement that anger or “acting out” was a common cause of UI in elderly.
2.6 | Ethical conflicts concerning care

Arguably, another important factor that contributes to elder abuse is the ethical conflict associated with caregivers’ duty of care to uphold care recipients’ rights to exercise autonomy, whilst protecting them from harm. The author found formal caregivers working in nursing homes struggled to allow residents to exercise choice and autonomy related to bladder and bowel function (Ostaszkiewicz, O’Connell, & Dunning, 2014). Moreover, staff and residents’ opinions about continence care needs did not always align, and many residents rallied against being care dependent. A common area of disagreement related to the risk associated with walking to the toilet. This difference of opinion generated considerable tension.

Smethye, Kirkevold, and Engedal (2016) described a similar situation for family caregivers of people with a diagnosis of dementia who were living at home. Using a qualitative, hermeneutic design, based on nine cases, the researchers identified ethical dilemmas for family caregivers in terms of their desire to balance autonomy with safety and well-being for the person in their care.

The idea that some caregiving relationships are characterised by ethical conflicts is not new. As early as 1985, researchers described food refusal among nursing home residents as a double-bind conflict for nursing home staff (Akerlund & Norberg, 1985). Another common day-to-day autonomy conflict occurs when caregivers and care recipients differ in their opinions about care-dependent person’s need for help with bathing. Horst et al. (2006) described the traditional practice of forced and routine bathing in nursing homes as a difficult and distressing undertaking for carers and care recipients alike.

3 | Care Recipient Factors

3.1 | Frequent and severe incontinence

Older people with complex health problems who are care-dependent are more likely to experience incontinence than other people, and their symptoms are more likely to be frequent and severe (Drake et al., 2017; Wagg et al., 2017). There is a significant correlation between the prevalence of UI and FI and physical and cognitive functional decline. Fifty-six percent of people experiencing UI in the last 3 months of their lives, and this rises to 72% for those who are ADL dependent and 71% for those with cognitive impairment (Jakobsson, Gasto-Johansson, Ohlen, & Bergh, 2006).

The practical implications of caring for a person with frequent and severe incontinence are largely unchartered, and there is no known research that quantifies the impact of UI or FI on carers by type, frequency or severity. In either the community or institutional care settings. Nevertheless, it is highly probable that more frequent and more severe incontinence is associated with poor health outcomes for informal carers that diminish their caregiving abilities. For example, symptoms such as nocturia warrant carer intervention, and potentially interfere with the quality and duration of their sleep. Moreover, as people void many times throughout the day, providing continence care requires a commitment to providing regular, reoccurring support. These issues are unlikely to be salient for formal carers.

3.2 | Cognitive Impairment

People with a diagnosis of dementia tend to struggle to maintain continence, particularly as the diagnosis progresses (Apostolidis et al., 2017). Global damage to the brain caused by dementia interferes with neural control of the bladder and/or bowel (Østbye, Hustekar, & Sykes, 2002). The pathophysiological changes associated with dementia typically cause a loss of ability to locate and use the toilet independently, and misjudgments about the nature of continence care. This factor may explain why people with a diagnosis of dementia have high continence care needs in the last 24 months of life (Covinsky, Eng, Lui, Sands, & Yaffe, 2003).

Assisting a cognitively impaired person to maintain continence or manage incontinence can be a challenging task, particularly if the care recipient does not understand the nature of the care (Hutchinson, Leger-Kraft, & Skodol Wilson, 1996; Ostaszkiewicz, 2013; Upton & Reed, 2005). According to the findings of a phenomenological study of carers’ experiences of caring for a family member with dementia and incontinence, "incontinence within the setting of a dementing illness invariably bears on comparison with that of compose ments individuals: that is it presents as a behavioural problem that is physically and psychological draining/demanding on the carers" (Upton & Reed, 2005 p. 1201). Moreover, in some cases, carers’ efforts to provide continence care trigger highly emotive responses that cause considerable distress for both carers and care recipients (Hutchinson et al., 1996; Ostaszkiewicz, 2013; Upton & Reed, 2005). An ethnographic study of the management strategies formal and family carers used for people with Alzheimer’s disease found “toileting emerged as a complex event with many stages, as unaesthetic and unpleasant for carers and clients, and occasionally resulted in catastrophic reactions” (Hutchinson et al., 1996. p.18).

3.3 | Rejection of care

In some cases, individuals with BPSD reject or resist care. Rejection of care behaviours includes verbal refusal or argumentative behaviours, body positioning, gestures or physical resistance that can escalate into combative or physically aggression (Ishii, Streim, & Saliba, 2012). A Norwegian study that investigated the relationships between specific factors and abuse and neglect in nursing homes found resident aggression increased the probability of all three types of abuse: emotional, physical and neglect (Malmedal, Hamrevold, & Saveman, 2014).

Activities such as bathing, toileting, grooming, eating and dressing commonly trigger rejection of care behaviours. They are more prevalent among people with severe dementia or functional impairment (Ishii et al., 2012). Restricting a care-dependent person’s right to exercise physiological autonomy is likely to trigger rejection of care behaviours. In one of the very few studies that has explored the acceptability of continence care interventions for people with dementia, Jiracek and Tempkin (2001) found any family carers were unable to comply with recommendations to prompt the person to the toilet, due to the person’s resistance. Hence, rejection of care is a critical issue that affects caregiving. Whilst rejection to care alone does not cause
3.4 A history of physical or psychological trauma

According to Muller-Hergl (2004), incontinence and providing continence care are likely to revitalise themes of dependency for both parties. "Generally speaking, dementia and incontinence highlight never-challenged or questioned relationships between carers and persons with dementia and lead these relations with old, unresolved conflicts and tensions" (Muller-Hergl, 2004, p. 113). As such, the care recipient and the carer could find themselves enmeshed in a power struggle over order and cleanliness, reminiscent of the power fights between parents and children.

Dependence on another person for help with bladder and/or bowel function is likely to trigger profound emotions for any person, particularly if the assistance is provided by a person from the opposite gender or if it objectifies the person. The author suggests these negative emotions are more likely for people with a history of prior physical and/or psychological trauma, particularly a history of sexual abuse. By necessity, the personal nature of some continence care activities means that carers breach social norms about touch and body boundaries. In such situations, the task of providing continence care can be incredibly difficult and stressful for both parties. Indeed, the entire process may be overwhelming and lead to abuse.

In a discourse analysis about the impact of early-life trauma in nursing home residents, Anderson, Fields, and Dobb (2011) claim an "early-life trauma can erode an older person's coping resources and capabilities, leaving older adults particularly vulnerable to the emergence or re-emergence of problematic reactions to early-life trauma" (p. 756). The trauma can be broad ranging. The challenges associated with caregiving for people with a history of trauma are best illustrated in literature on caregiving for holocaust survivors. David and Pelly (2003) describe strong negative reactions among ageing holocaust survivors to the experience of undergoing invasive medical procedures or relocating to a nursing home. However, even "seemingly benign activities such as assisting an older Holocaust survivor with showering may trigger memories of the gas chambers in concentration camps, resulting in anxiety, fear, and refusal. Other seemingly benign activities or environments, such as using public restrooms or waiting in line, may again trigger memories of the conditions endured during the Holocaust" (Anderson et al., 2011, p. 756).

Although distressed behaviours do not and should not necessarily lead to abuses in care, the caregiving encounter nevertheless, requires skilful management. Failure to respond effectively to a distressed person's reactions can easily spiral out of control and result in the use of force or coercion.

4 SOCIAL FACTORS

4.1 The stigmatised nature of incontinence

Incontinence confounds social expectations of bodily control and shared beliefs about appropriate behaviour. It is a stigmatising condition that typically causes people to attempt to maintain independent bladder and bowel function, conceal the incontinence and self-manage (Hägglund & Wadensten, 2007; Teunissen & Lagro-Janssen, 2004). A Grounded theory study about the cognitive, psychosocial and behavioural aspects of living with UI in nursing homes found many residents attempted to conceal their incontinence, which was due in part to a fear of being alienated by staff. The researchers interpreted their behaviour as a cognitive effort to preserve their dignity and protect their social integrity (Robinson, 2000).

As dementia progresses, it becomes increasingly difficult for the person to self-manage incontinence or conceal their incontinence. In shared living environments, such as nursing homes, a person's incontinence becomes public when staff or family members find soiled or wet pads or clothing in a concealed location. As previously stated, if carers interpret the care recipient's efforts to self-manage and conceal their incontinence as "difficult behaviour," or believe they are voluntarily incontinent to gain attention, continence care interactions can be characterised by considerable tension and may lead to punitive care.

4.2 Social taboos and cultural norms

According to Isakson (2000), "the social norms and cultural symbols that surround the intimate parts of the body affect the way care work is organised, gendered, culturally understood, and socially stratified" (p. 2). Providing continence care is complicated by the fact that it involves breaching social rules about privacy, nakedness and touch. It may also involve a change in family and/or gender relationships, for example, where a daughter provides continence care for her father, or a son for his mother.

In most societies, nakedness and touching another person's genital area are linked to sexual intimacy. This touch may be interpreted as a profound comfort, a welcome sexual advance, or as a violation. Carers must engage in considerable emotion work to reduce tensions and stress associated with negotiating these social taboos. Whilst providing continence care, nurses (and carers) must establish safe and respectful boundaries with patients.

Providing continence care is also complicated by the cultural social taboos and cultural norms that link incontinence with a lack of cleanliness, feelings of disgust, shame and humiliation, helplessness, powerlessness and associated anger (Isakson, 2000). Based on early and limited research about nursing home residents' experiences, the way continence care is provided has a profound effect on care recipients' feelings (Bjurbrant Bjergersson, Hammar, Widertors, Hallberg, & Athlin, 1993). Bjurbrant Bjergersson et al. (1993) found female nursing home residents' feelings about UI and about being dependent on nurses to change their pads, alternated between shame and guilt, dependency and independency, security and insecurity and discomfort and comfort. The researchers hypothesised that the women were in a continuous state of vulnerability concerning their sense of value and autonomy, which was influenced by the approach that nurses adopted when interacting with them (Bjurbrant Bjergersson et al., 1993). To provide continence care, carers must find a way to deal with care recipients' emotional distress.
4.3 | The private nature of continence care

A further social consideration is the private nature of continence care. Although it may evoke complex feelings, continence care is a culturally invisible kind of care (Isakson, 2000). This may be because "cultural rules for appropriate behaviour do not allow talking aloud about such experiences" (Isakson, 2000: p. 14). Twigg (2000) stated, "bodywork [personal care and continence care work] is potentially demeaning work, and nurses go offstage to perform it" (p. 405) ... and "the dirty work of care is hidden in order that the institution can display the 'product' of its caring regime in the form of the 'lounge standard resident'" (p. 406).

Whilst this may be the case, it may also relate to a shared social value about protecting people's privacy. Nursing codes of practice endorse patients' rights to privacy and confidentiality as an ethical and legal obligation. The value placed on protecting a person's privacy related to incontinence may also explain why it is that family carers delay seeking help for their care recipients' incontinence (Drennan et al., 2011; Lobchuk & Rosenberg, 2014). The broader social implications of the concealed or the offstage nature of continence care are that the quality of care remains hidden from public scrutiny. Abuse is more likely to occur behind closed doors.

5 | DISCUSSION

Current theoretical explanations for elder abuse emphasise the quality of the relationship between the carer and the care recipient, particularly in community settings (Johannesen & LoGiudice, 2013). Attention is drawn to caregiver stress in the context of dependency, abuser psychopathology, intergenerational transmission of violence, external stress and social isolation (Biggs et al., 2009; Yan & Tang, 2003). Notwithstanding the contribution of this knowledge, the model of risk factors for elder abuse described in this study conceptualises causal and contributing factors between incontinence, care dependence, and physical elder abuse, psychological/emotional elder abuse and/or elder neglect.

The model is applicable to the care of any older person with a health condition that causes them to depend on a carer for assistance with bladder and/or bowel elimination. It is also applicable to caregiving in either an institutional or family context, that is formal or family caregiving. Although there are important differences between formal and family carers' experiences of caregiving, the model suggests many aspects of the caregiving experience are similar, particularly with respect to the emotional component.

The emotional labour of caregiving is a well-known phenomenon, first described by Hochschild (1983). Hochschild (1983) differentiated between "emotional labour" that employers require in paid jobs and the emotional labour involved in unpaid efforts of family and personal life. However, in both situations, Hochschild identified an intentional management and display of one's own feelings, usually undertaken to influence the feelings of others. Carers who provide continence care should be aware, not only of the emotions the care recipient, but also of the emotions they bring to the caregiving encounter. Ideally, they should have the opportunity to debrief about caregiving encounters they find challenging.

There are a number of important implications of the model. The first of these is that it should not be assumed that carers (formal and family) necessarily know how to provide continence care and/or deal with the aesthetically difficult realities of bodywork or that they know how to manage their own or other peoples' feelings of embarrassment, shame, humiliation and/or a sense of disgust. Knowledge about incontinence and its management is low among both formal and family carers. To minimise the potential for harmful caregiving associated with continence care, formal and family carers need education about therapeutic communication strategies that build a care recipient's resilience and promote their physiological and psychological well-being in the caregiving encounter. This education should also help carers develop an empathetic understanding about basic human emotional responses to incontinence and care dependence and to recognise the effect of these emotions on their own behaviours, and those of the care recipient.

Secondly, in people with a diagnosis of dementia or some other form of cognitive impairment, providing continence care should be recognised as a common antecedent for distress by the care recipient. Therefore, formal and family carers should be equipped with the knowledge and skill to not only manage care recipients' variable responses, but ensure caregiving does not escalate into a struggle for power and control. All carers of people with cognitive impairment should be educated about BPSD and learn how to help care recipients adjust to changes in their bodily function that affect their identity, autonomy, control and independence. In particular, carers should view rejec­tion of care and other BPSD as an attempt to communicate unmet needs. (Algase et al., 1996). It is also important to educate carers about the possibility that providing continence could rekindle painful memories for some care recipients who have experienced a past traumatic event such as abuse. Understanding the impact of past trauma on older adults should allow carers to take a proactive approach to care planning and caregiving.

The author suggests that ethical conflicts about continence care can result in coercive or abusive care if the conflict is poorly managed. Restricting any person from exercising their right to use the toilet is likely to trigger rejection of care behaviours, as is providing continence care that is interpreted as intrusive. By contrast, enhancing personal control in everyday life is associated with improved quality of life (Duncan-Myers & Huebner, 2000). In an effort to support nurses and care workers identify and meet the continence care needs of individuals with complex health conditions, the author designed a conceptual framework that is underpinned by two core concepts: "dignity" and "care." It is hoped that the implementation of the "Dignity in Continence Care Framework" will optimise well-being, autonomy and choice in continence care for people who are care dependent, and thereby minimise the potential for abuse in continence care (Ostaszekiewicz, 2017).

If caregiving is to be sustained, incontinence needs to be recognised as a clinically important issue. Therefore, screening and
assessment processes for care-dependent older people should prompt sensitive enquiry about the frequency and severity of their continence care needs. A recent survey of 180 hospitalised patients aged 60 years and older with serious illnesses found 67% considered bowel and bladder incontinence to be a state the same as, or worse than death (Rubin, Buehler, & Halpen, 2016). Despite the value individuals place on being continent, many nurses do not consider incontinence to be a clinically important issue (Booth, Kumlien, Zang, Gustafsson, & Tolson, 2009; Cooper & Watt, 2003).

Nurses represent the largest group of healthcare providers in most countries and are likely to care for people with incontinence and continence care needs on a regular basis. They also play a key role in supporting formal and informal carers. Nurses should adopt an active approach to incontinence that is informed by evidence-based guidelines about care finding and treatment (Wagg et al., 2017). They should also be aware how their actions can either inhibit or enhance the older person’s exercise of autonomy related to bladder and bowel function.

In so far as the model elucidates possible associations between incontinence, continence caregiving, and physical and psychological/emotional abuse, and/or neglect, it should inform future efforts to prevent abuse. The duality of incontinence and care dependence should be included as a potential risk factor in efforts to systematically prevent, identify and intervene for elder abuse.

6 | CONCLUSION

As the population ages and the number of people requiring skilled care rises, it is increasingly important to find ways to support all carers so that they have the knowledge and skill to provide continence care that optimises care recipients’ autonomy and minimises the potential for elder abuse. The MADE-CC described in this study provides insights into the possible risk of elder abuse posed by incontinence and care dependence. It is equally applicable to continence caregiving by both formal and family carers, to care recipients with varying health problems. The model adds to the existing body of research about the multiple interacting individual, relationship, community and societal factors that place care-dependent older people at risk of abuse.

<table>
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<tr>
<th>Implications for practice</th>
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<tr>
<td>• Providing and receiving continence care typically evokes anxiety for the person receiving such care as well as the person providing such care</td>
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<tr>
<td>• Carers and nurses have a key role to play in promoting care-dependent individuals' rights to physiological autonomy</td>
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<tr>
<td>• To ensure patients feel dignified, safe and respected during continence care encounters, it is important that carers and nurses are aware of the causal and contributing links between incontinence, care dependence and elder abuse</td>
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</table>

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