

Bladder and Bowel Symptoms, Dementia and Responsive Behaviours: An Integrative Review

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Abstract

Background: Dementia has become a worldwide healthcare and research focus. However, there is currently little research linking bladder and bowel symptoms with responsive behaviors in dementia. Aim: The aim of this integrative review was to identify research literature that explores the role of bladder and bowel symptoms as triggers of responsive behaviors in persons with dementia. **Design:** This integrative review was informed by the method of Whittemore and Knafl and guidelines by Torraco. Methods: Electronic databases of Ovid Medline, Embase, PSYCInfo, Cochrane, EBSCO/CINAHL, Scopus, and Web of Science were searched. Five studies met inclusion criteria. They were assessed for quality using the Mixed Methods Appraisal Tool. Studies were compared, analyzed, and synthesized. Results: The categories developed were: (1) bladder and bowel symptoms examined, (2) relationship of behavior measurement to responsive behaviors, and (3) associations between incontinence and behaviors symptoms. Conclusion: The findings of this investigation demonstrate a limited understanding of the association between bladder and bowel symptoms with responsive behaviors. The conceptualization of behaviors as problems was evident in the studies. This conceptualization is not reflective of a contemporary view of behaviors as an expression of an unmet need. Future research is needed to understand the association between bladder and bowel symptoms and responsive behaviors. Keywords: dementia, lower urinary tract symptoms (LUTS), fecal incontinence (FI),

responsive behaviors (RB), quality of life (QoL)

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Approximately 50 million people around the world are living with a dementia diagnosis (World Health Organization, 2020). Given the numbers of individuals living with dementia, research must rise to the challenge of addressing the situations that clinicians and caregivers face as they try to provide both quality care and care that enhances quality of life (QoL) for individuals living with dementia. Many individuals with dementia respond through behaviors to an unmet need that they are unable to communicate in other ways (Clifford & Doody, 2018; Herron & Wrathall, 2018). Information aimed at clinicians and caregivers on addressing responsive behaviors often suggest toileting among other strategies for some behaviors (Alzheimer Europe, 2014; Alzheimer Society of Canada, 2019). However, a recent systematic review on strategies to address behaviors in persons with dementia identified multiple strategies, but did not address bladder and bowel symptoms as triggers of behaviors (Abraha et al., 2017). The research evidence to support clinical and caregiver information is unclear.

Background

Bladder and bowel symptoms are composed of lower urinary tract symptoms (LUTS), fecal incontinence, and constipation. LUTS, includes storage symptoms (e.g. urgency and incontinence), voiding symptoms (e.g. hesitancy) and post-voiding symptoms (e.g. incomplete emptying) (Abrams et al, 2002; Abrams et al., 2009). Fecal incontinence is defined as involuntary passage of stool, with subtypes of urge (involuntary loss of stool associated with the urgent need to defecate), passive (involuntary loss of stool with no warning) and seepage (normal defecation followed by leakage of stool) (Bliss et al., 2017; Shaw & Wagg, 2021). Double incontinence, fecal incontinence and urinary incontinence that occur together, increases in older persons living with dementia when compared to those without dementia (Averbeck et al., 2017; Chiang et al., 2015; Schüssler et al., 2016). Functional or disability-associated incontinence is urinary incontinence or fecal incontinence related to functional inability to reach a toilet/urinal in time due to a physical, cognitive and/or behavioral impairment (Shaw & Wagg, 2021; Bliss et al., 2017). Constipation and fecal loading are thought to worsen both UI and FI in older persons (Shaw & Wagg, 2021).

There is a higher prevalence of urinary incontinence in people living with dementia, which may be associated with behaviors such as voiding in inappropriate places and hiding soiled clothing (Averbeck et al., 2017; Drennan et al., 2011). Older persons with cognitive impairment often have urinary incontinence (Wagg et al., 2017). FI in persons with dementia can be associated with factors such as medication side effects, physical disability, environment, actions and attitudes of caregivers, and neuropsychological factors (Goodman et al., 2017).

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Behaviors in dementia are common, affecting up to 90% of people with dementia (Radue et al., 2019). Behaviors have been variously labeled as neuropsychiatric symptoms of dementia (Radue et al., 2019; Roitto et al., 2019), behavioral and psychological symptoms of dementia (BPSD) (Cerejeira et al., 2012) and responsive behaviors (Herron & Wrathall, 2018). Responsive behaviors are sometimes clustered under the term neuropsychiatric symptoms of dementia, which can include symptoms such as apathy, delusions, and agitation (Radue et al., 2019). Others define responsive behaviors as expressions of unmet needs related to things such as sleep, pain, hunger, and toileting (Clifford & Doody, 2018; Herron & Wrathall, 2018). Caregivers may also see response behaviors that include wandering, calling out, and verbal or physical aggression. Such symptoms are associated with decreased quality of life (Chiang et al., 2015).

A realist review conducted by Buswell et al. (2017) aimed to understand the causal relationship between focused interventions and improved management of fecal incontinence in nursing home residents with dementia. The authors identified few studies, with two over 30 years old. Interventions focused on cueing the person with dementia and making environmental improvements. This realist review did not explore how bladder and bowel symptoms influenced responsive behaviors in persons with dementia.

Dementia researchers often encounter barriers in collecting subjective data from participants with dementia. One barrier related to bladder and bowel symptoms and responsive behaviors is the that both dementia and continence are stigmatized (Drennan et al., 2011; Hewer-Richards & Goodall, 2020). AUTHOR (2018) suggest that some nurses lack knowledge in continence care, creating a barrier to implementation of evidence-based interventions. In spite of these barriers, research on how bladder and bowel symptoms trigger responsive behaviors is needed to inform clinicians and caregivers on preventing responsive behaviors and addressing them using evidence-based non-pharmacological interventions. Nursing involvement in continence care should be encouraged and supported so that issues can be identified and prioritized, and so that nurses can educate and empower individuals with dementia and their care partners (AUTHOR, 2018). An integrative review was conducted to understand how bladder and bowel symptoms are related to responsive behaviors in persons with dementia,

The Review

Aim

The aim of this integrative review was to identify research literature that explores the role of bladder and bowel symptoms as triggers of responsive behaviors in persons with dementia.

Methods

Integrative reviews synthesize relevant literature, generate new knowledge on a topic, and provide a greater foundation for further research and evidence-based nursing practices (Torraco, 2005; Whittemore & Knafl, 2005). The literature review was conducted using Whittemore and Knafl's (2005) five-stage methodology for conducting an integrative review, as well as guidelines presented by Torraco (2005). The steps of the review included: (1) identifying the problem related to the topic of interest; (2) conducting a literature search; (3) evaluating the data; (4) analyzing the data and (5) synthesizing the data to presented a new understanding of the topic.

Inclusion and Exclusion Criteria

Studies of any design (qualitative, quantitative, mixed methods, systematic or scoping reviews) from any country, published in peer-reviewed journals in the English language, were included. There was no time limit set for the search. Accepted studies included those looking at behavior triggers. The included articles discussed or examined a relationship or association between bladder and bowel symptoms and responsive behaviors in older persons with dementia living in any setting. Exclusion criteria were opinion articles, non-research articles, and articles that were not published in English.

Search Strategy

The search strategy was guided by a health services librarian. Databases searched include Medline, EMBASE, PSYCInfo, Cochrane Library, EBSCO/CINAHL, SCOPUS, and Web of Science. Reference lists of relevant articles were hand-searched to identify additional studies for the review. The key terms and Medical Subject Heading Terms (MeSH) used for conducting the search included boolean operator terms for: dementia or Alzheimer's; responsive, reactive, agitated, aggressive, disturbed or neuropsychological behaviors or symptoms; behavioral and psychological symptoms of dementia (BPSD); urinary incontinence, fecal incontinence, lower urinary tract symptoms (LUTS), urinary tract infection, urinary urgency, urinary hesitation, or incomplete emptying.

Search Outcomes

The initial search yielded 505 results. Results were downloaded to Covidence software, and 137 duplicates were removed. The remaining 368 articles were screened by title and abstract. Of those screened, 88 publications were further assessed for eligibility by a full text review by the first two authors. Following full-text screening, eight studies were further evaluated and discussed by the first two authors in terms of meeting inclusion criteria. Reference lists of these articles were hand-searched for any further

potentially relevant studies. This resulted in a total of five studies (four from the original search and one from the hand-search) included in the integrative review.

Figure 1: PRISMA diagram



Quality Appraisal

The five included studies were assessed for quality using the Mixed Methods Appraisal Tool (MMAT) 2018 version (Hong et al., 2018). The MMAT screens for clear research questions and data relevance to the research questions of the study. Further appraisal questions are dependent on the study design. Responses to the questions for each appraised article can be "yes," "no," or "can't tell." Overall scores were not calculated as recommended by the tool authors. Individual appraisal of each of the included studies can be seen as part of Table 1. **Table 1:**

Authors/ Year/ Country	Study Design & Aim	Sample Size and Characteristic	Key Findings	Implications & Recommend- ations	Quality Appraisal
Alcorn et al. 2014 Scotland	Cross- sectional quantitative study that used logistic regression to identify key cognitive and behavioral associations and risk factors for urinary incontinenc e in community dwelling persons with Alzheimers Disease.	N= 284 home dwelling persons with dementia from the Scottish Dementia Research Interest Register (SDRIR) with continence data.	Of behaviors measured, agitation (OR 1.29, 95% CI 1.09–1.53 per point increase) and disinhibiti on (OR 1.36, 95% CI 1.06–1.74 per point increase) were significantl y associated with urinary	The authors noted that the causal direction between agitation and incontinence is unclear. Persons with dementia exhibiting agitation may ignore internal cues to void, or urinary incontinence may contribute to agitation.	This study scored well in 5/5

Characteristics of Included Studies

				
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			incontinen ce. Cognitive factors of attention and orientation , verbal fluency, as well as age were also significantl y associated with urinary incontinen ce.		
Leonard et al. 2006 United States	Cross- sectional correlationa l study that used logistic regression to explore potentially modifiable resident characteristi cs associated with physical aggression, in order to correlate them with verbal aggression.	N=103,344 nursing home residents from five states including California, New York, Ohio, Pennsylvania, and Texas.	Of the potentially modifiable factors measured, constipatio n (adjusted OR 1.3, 99% CI 1.2-1.5) was associated with physical aggression but not verbal aggression	The authors noted that although an association between constipation and physical aggression was identified, it was unclear if the association was related to other predisposing factors such as medications, symptoms related to constipation, or interventions such as	This study scored well in 5/5

			Depressiv e symptoms, delusions, and hallucinati ons were also associated with physical aggression as well as verbal aggression	suppository administration.	
Li et al. 2019 Taiwan	Cross- sectional correlationa l study that used logistic regression to explore potentially modifiable resident characteristi cs associated with physical aggression, in order to correlate them with verbal aggression.	N=226 long- term care residents with dementia.	UI was found to have a relationshi p to depression , cognitive function, and ADL, but not to age or agitated behaviors (r=06, p=.348). ADL performan ce was found to	The authors noted that there are few studies that have explored factors directly or indirectly associated with urinary incontinence in older adults with dementia. They referenced the study by Alcorn et al. (2014) and implied the need for further similarly focused research.	This study scored 4/5

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			be most significant ly associated with UI.		
Na et al. 2015 South Korea	Cross- sectional quantitative study that used logistic regression to evaluate the prevalence of urinary incontinenc e and determine the neuropsych ological characteristi cs of individuals with Alzheimers Disease and urinary incontinenc e.	N=464 individuals from outpatient dementia clinics in hospital settings.	Initial data analysis showed that NPI was potentially associated with AD/UI+** however after adjustment there was no significant associatio n between neuropsyc hiatric symptoms/ behavioral and psychologi cal symptoms of dementia and AD/UI+ (OR 1.00, 95% CI	The authors recommended further longitudinal research with larger numbers of participants as well as similar research that focuses on individuals with other types of dementia (not just AD).	This study scored well in 5/5.

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			0.98- 1.01). Cognition and ADLs were the only variables found to be associated with Alzheimer s Disease and urinary incontinen ce.		
Spector & Jackson 1994 United States	Prospective descriptive study that used logistic regression to re- examine factors associated with the occurrence of disruptive behaviors such as wandering, noisiness, and abusiveness.	N=3,351 NH residents.	Incontinen ce was determine d to be significant ly associated with wandering (OR 1.57, CI 95% 1.03-2.	The authors of this study recommended controlled research studies to further evaluate individual resident characteristics and interventions from staff members, and the extent of their association with disruptive behaviors.	This study scored well in 5/5

Data Analysis

Whittemore and Knafl (2005) describe the data analysis phase for integrative reviews as data reduction, data display, data comparison, conclusion drawing and verification. The first author of this review kept notes throughout the review process. The first and second authors frequently discussed the data, coming to a consensus on key information from each included study. Data reduction included organizing information from each study into a data extraction table which delineated information from each study. The synthesis of the data including conclusion drawing can be found in the findings section, with verification in the discussion section.

Findings

All studies included in the review were quantitative descriptive studies. The most recent was published in 2019. There were two other studies published within the last 10 years, and one study published 15 years ago. The oldest study was published more than 25 years ago, in 1994. The two most dated studies were conducted in the United States. The other studies were conducted in South Korea, Taiwan, and Scotland. Studies included data on a sample size that ranged from 284 to 103,344. Participants ranging from 60 to a mean age of 82 and from settings that included community dwelling, hospital, and nursing home. None of the studies used the term responsive behaviors, rather they used the term behaviors.

In terms of appraisal of quality, the included studies met most or all criteria for the study type using the MMAT tool (Hong et al., 2018). All the included studies were observational designs in which associations between factors or characteristics and behaviors observed in persons with dementia were explored. As none assessed effectiveness of interventions, it is difficult to assess level of evidence for this group of studies using the Oxford (OCEBM Levels of Evidence Working Group, 2011) or Johanna Briggs (Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party, 2014) criteria. Grading level of evidence is not required in the method followed for this review, although quality appraisal is required (Whittemore & Knafl, 2005).

Three broad categories were developed to summarize and synthesize key concepts from the included studies. The categories are: (1) bladder and bowel symptoms examined, (2) relationship of behavior measurement to responsive behaviors, and (3) associations between incontinence and behaviors.

Bladder and Bowel Symptoms Examined

No studies included an array of lower urinary tract symptoms, instead they focused only on incontinence. One study included constipation, but not fecal incontinence, reporting an association between constipation and physical aggression (Leonard et al., 2006). Three studies included only one of the lower urinary tract symptoms - urinary incontinence - as a variable (Alcorn et al., 2013; Leonard et al., 2013; Li et al., 2019). Incontinence was often represented as a dichotomous variable, being identified as either continent of urine or not. Only one study (Na et al., 2015) identified types of UI (stress, urge, overflow, and functional), however no data were provided on a sub analysis of types of UI and behaviors measured on the Neuropsychiatric Inventory (NPI). One study identified the proportion of participants who were incontinent (Spector & Jackson, 1994), without identifying if this was urinary or fecal incontinence. *Relationship of Behavior Measurement to Responsive Behaviors*

None of the included studies defined behaviors in dementia from the perspective of as an expression of unmet needs, that is responsive behaviors. Two of the studies used the NPI, finding both agitation and behaviors significantly associated with UI (Alcorn et al., 2013; Na et al., 2015). One study used the Cohen Mansfield Inventory reporting agitation and UI as not related (Li et al., 2019). Another study utilized the Resident Assessment Instrument-Minimum Data Set (RAI-MDS) data using constipation, and UTI as variables in evaluating associations with physical or verbal aggression (Leonard et al., 2013). The oldest study (Spector & Jackson, 1994) included behaviors such as wandering, being noisy, or abusive which were seen as related to incontinence. These authors did not conceptualize behaviors as reflecting unmet needs.

Associations Between Incontinence and Behaviors

Four of the five studies examined associations between incontinence and behaviors (Alcorn et al., 2014; Li et al., 2019; Na et al., 2015; Spector & Jackson, 1994). One study looked at associations between constipation and behaviors (Leonard et al., 2006). While each of the other studies explored an association between incontinence and behaviors. It is important to note that some of the findings conflicted with others or were unclear. For example, Alcorn et al. (2014), Leonard et al. (2006), and Spector and Jackson (1994) found an association between incontinence or constipation and agitation, aggression, or disruptive behaviors, while the other two studies did not. Alcorn et al. (2014) also questioned the causal relationship between incontinence and agitation.

Discussion

The key finding of this study is that there is a tenuous association between behaviors and bladder and bowel symptoms, with little research undertaken to clarify the reasons for the association. The description of behaviors in the studies implied that they

were a problem rather than an expression of an unmet needs. Current information on public websites about responsive behaviors suggests a possible relationship between bladder and bowel symptoms (Alzheimer Europe, 2014; Alzheimer Society of Canada, 2019). Yet we have discovered that there are few studies that have explored this relationship, despite these suggestion on public websites.

The lack of consistency between study findings about the relationship between bladder and bowel symptoms and responsive behaviors demonstrates that there is limited research available to understand the association. Moreover, most of the studies were more than 10 years old and some had conflicting results. Only Na et al.'s (2015) study identified types of incontinence. Yet, these authors dichotomized UI (as present or absent) for the analysis. None of the other studies included any other LUTS except incontinence. While UI is one important component of LUTS, other symptoms like urgency, incomplete emptying, or nocturia could trigger responsive behaviors for individuals with dementia. People who do not have dementia might be able to express physical discomfort or concerns about their health, but those with dementia may lack the ability to express their need to toilet, due the cognitive changes associated with dementia Herron & Wrathall (2018). They may instead attempt to express their needs through behaviors such as wandering, calling out, or acts of aggression. Thus, there is much on the topic of bladder and bowel symptoms and responsive behavior that has not been explored. This suggests there is a research gap.

None of the included studies described behaviors as responses to an unmet need. The studies tended to examine behaviors such as agitation or wandering from the perspective of these being problems or disruptive. Some of the studies (Alcorn et al., 2013; Li et al., 2019; Na et al., 2015) used instruments to measure behaviors (NPI and Cohen Mansfield Inventory) from the conceptualization that behaviors in dementia are problematic. This is likely due to the age of the studies, which may reflect the dominant view of behaviors in dementia at the time. More current views, as described by Clifford and Doody (2018) and Herron and Wrathall (2018), identify that behaviors exhibited by persons living with dementia are expressions of unmet basic human needs – responsive behaviors. Future research should include examination of the association between bladder and bowel symptoms and responsive behaviors. As well, these studies need to include a range of LUTS, such as urgency and nocturia and not be limited to the dichotomous view of incontinent or continence.

The stigma surrounding bladder and bowel symptoms as well as dementia discourages open conversations among clinicians and caregivers as well as interest in conducting research (Cole & Drennan, 2019; Drennan et al., 2011; Hewer-Richards & Goodall, 2020; Ostaszkiewicz et al., 2016). Open communication with individuals and their families, as well as among care teams, is vital to improving understanding of

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concerns related to continence and responsive behaviors in dementia (AUTHOR et al., 2018; Ostaszkiewicz et al., 2016). Research that examined bladder and bowel symptoms and responsive behaviors could support the development of evidence informed care practices.

Implications

Further research assessing the association of bladder and bowel symptoms with responsive behaviors in dementia is needed. Nurses need to be aware that strategies such as toileting suggested in information about managing responsive behaviors does not appear to be grounded in research at this time. This does not mean that such strategies are not effective in practice, only that we lack evidence to support the practice. Thus, using toileting to address responsive behaviors that are suspected to reflect bladder and bowel symptoms remains a reasonable clinical strategy. However, the effectiveness of such strategies needs to be evaluated on an individual basis in the clinical setting, and in research studies.

Limitations

This review was limited to studies published in the English language thus, relevant studies in other languages may have been excluded. The effectiveness of management strategies for bladder and bowel symptoms of persons with dementia was not explored in this review.

Conclusion

This integrative review is to the authors knowledge the first to attempt to examine research on bladder and bowel symptoms with responsive behaviors in dementia. The findings of this study demonstrated a limited understanding of the association between responsive behaviors and bladder and bowel symptoms. The conceptualization of behaviors as problems does not reflect a contemporary view of behaviors as an expression of an unmet need. Future research is needed to understand the relationship of bladder and bowel symptoms to responsive behaviors.

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