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### What do you say when a resident loses control?

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#### Abstract

The most humiliating experience an alert nursing home resident faces is unpredictable incontinence. Generally, nursing home staff perceive the event as inconsequential and follow procedures for cleaning up. Professional staff do not define this event as a psychological catastrophe and respond in a nonchalant manner. The premise for following this nonchalant path appears to be ageism. That is, staffs think incontinence does not breed humiliation among elders. It does. A review of literature supports this position. The critical question becomes, "How does a nursing home professional verbally and nonverbally respond to a resident upon experiencing incontinence for the first

time?" Based on a role playing experiment, effective responses to incontinence are discussed and analyzed.

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## Introduction

From working in nursing homes over the decades, I have witnessed bowel and bladder incontinence. Two critical biopsychosocial aspects of this event exist. First, this event is a normal part of terminal drop<sup>1</sup>. Bowel or bladder incontinence is a part of giving up on life. Here, terminal drop is the independent variable and incontinence is the dependent variable as illustrated in Figure 1.

### Figure 1

Figure 1

**Terminal Drop** —————→ **Incontinence**

The phenomenon is best illustrated by a person's conscious or subconscious desire to surrender life. The willingness to surrender one's life leads to a series of biopsychosocial characteristics such as a drop in IQ scores, disengagement from social interaction, bowel and bladder incontinence, etc. Within this scenario, little human service intervention is available or perhaps even appropriate.

Second, and much less obvious, bowel or bladder incontinence is the precursor to terminal drop. Here, incontinence is the independent variable and terminal drop is the dependent variable as illustrated in Figure 2.

### Figure 2

Figure 2

**Incontinence** —————→ **Terminal Drop**

The phenomenon is best illustrated by a person's physical inability to control one's bowel or bladder. The emotional devastation of bowel and bladder incontinence is so humiliating; a nursing home resident (or a person living independently in the community) no longer has the desire to live. This profound emotional devastation leads to terminal drop or passive suicide. Within this scenario, human service intervention has the potential of being successful. In institutional settings, where little privacy exists, the first response to the "accident" is critical. Role playing lays the foundation for a successful first response.

## Review of Literature with Commentary

To pursue this investigation, a review of literature is necessary to address several questions. These questions include:

- What are the emotional consequences of incontinence?
- What is the relationship between terminal drop/passive suicide and incontinence?
- What biopsychosocial variables predict incontinence?
- What damage is the result of incontinence?
- Is psychosocial intervention fruitful?

The review of literature is organized around addressing these types of questions.

## The Emotional Consequences of Incontinence

The literature on the consequence of bowel and bladder incontinence is unambiguous and supports common sense. Depression (Bogner, et. al, 2002; Corna & Cairney, 2005; Fultz, & Herzog, 2001; Heidrich, & Wells, 2004; Holroyd et al. 2004, Meade-D'Alisera, P., et al. 2001; Melville, et. al, 2005; Nygaard, et. al, 2003; Perry, McGrother, & Turner, 2006) and anxiety (Bogner, et. al, 2002; Corna & Cairney, 2005; Fultz, & Herzog, 2001) are a direct results of bladder and bowel incontinence. Regardless of living independently in a community (Bogner, et. al, 2002; Corna & Cairney, 2005; Fultz, & Herzog, 2001; Heidrich, & Wells, 2004; Meade-D'Alisera, P., et al. 2001; Melville, 2005; Nygaard, et. al, 2003; Perry, McGrother, & Turner, 2006) or in an institutional setting (Holroyd et al. 2004), the results remain the same. Psychological distress, usually in the form of anxiety and depression, will emerge as a consequence of bowel and bladder incontinence.

In addition to the emergency of anxiety and depression, Shaw (2001) offers a review of literature in which he notes that "stigmatization," reduced life satisfaction, and impaired quality of life exist. Willingness for community elders to leave their homes decreases. Disengagement is expedited. For nursing home residents, the emotional consequences appear to be more severe. Community elders can hide their "accident" whereas nursing home elders cannot. Feelings of helplessness and hopelessness are more profound among nursing home residents.

## Terminal Drop, Passive Suicide and Incontinence

One of the most comprehensive studies is the work of Holroyd-Leduc et al. (2004) where the authors content that two valid causal relationships exist as seen in Figure 3.

### Figure 3

Figure 3

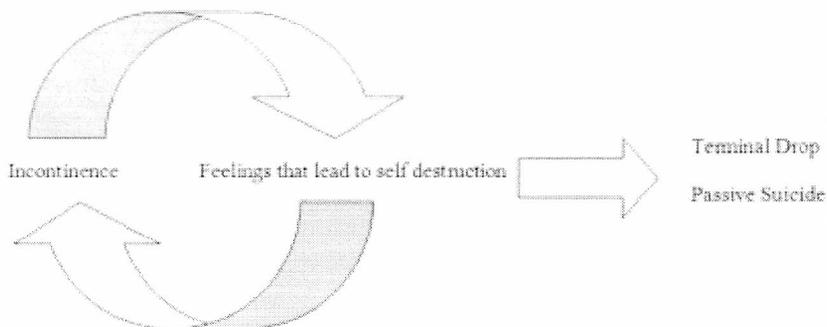


Within model 1, conditions associated with terminal drop induce a person from wanting or needing to control his/her bowel and/or bladder. Within model 2, the person experiences involuntal depression and/or anxiety inducing him/her to ask the question, "Is life worth living?" Their findings suggest that both models have emerged from their research as well as research cited in their review of literature. Essentially, they contend that both models are valid explanations. Since social gerontologists focus on linear mathematical models, the useful relationships between terminal drop/passive suicide and incontinence are cumbersome to express with state-of-the-art social science methodologies. However, there is an alternative explanation to their empirical findings.

An alternative explanation is that the relationship is less linear and more ecological. Figure 4 best illustrates this causal linkage.

Figure 4

Figure 4



First, an interaction variable exists. Incontinence and the self destructive feelings spin and perform as a single variable. Past research identifies incontinence as an independent variable and the psychological reaction as an intervening variable and vice versa.

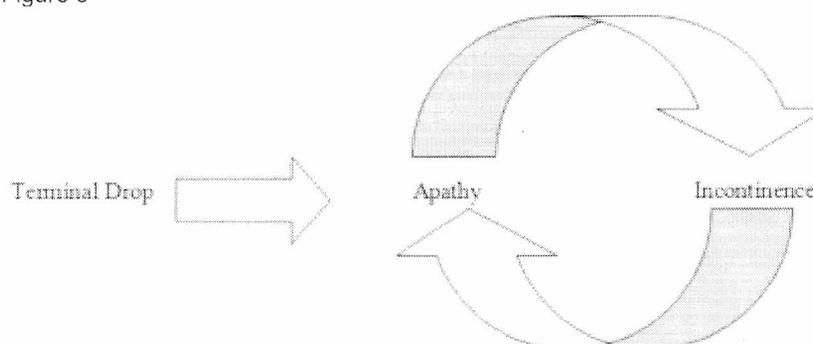
A psychological reaction emerges with the realization that one was not able "to act like an adult." Within our culture, a person will interpret incontinence as a regression to infancy. If a person is residing within independent community living, one can conceal the "accident." If a person is residing within an institutional setting, one cannot conceal the accident. The remorse is a "precipitating event" that leads to passive suicide and/or terminal drop. Within the model depicted in figure 4, the first cause is irrelevant. The need for intervention is apparent without having a clear articulation of first cause. Incontinence clearly leads to feelings of involuntal depression and/or anxiety which emerge as a consequence of progressing toward a new phase of life

that is dominated with loss of control and dependency for assistance in Activities of Daily Living. The circular or ecological model appears to be a more accurate representation of nursing home and independent living realities.

Conversely, terminal drop lays the foundation as an interactive relationship between apathy and incontinence as illustrated in Figure 5:

**Figure 5**

Figure 5



Apathy for living perpetuates a variety of behavioral manifestations, including incontinence. Sadly, by the time a practitioner (usually a nurse or a social worker) identifies terminal drop, no psychosocial intervention can alter the course. In addition, an ethical dilemma emerges: "Does an elderly person have the right to self-determination when facing death's door? Does he/she have the right to open that door?" The question remains unanswered. The best option for the practitioner is to focus on the dynamics found in Figure 4 rather than Figure 5.

### **Biopsychosocial Variables Predict Incontinence**

In order to provide effective intervention, it is helpful to know the predictor variables. In most social science research, demographic variables are often used as a foundation for establishing cause or explanation. In examining bowel and bladder incontinence, such variables offer little to our understanding. For example, cultural background does not help explain the existence or the degree of psychological distress. There is no difference between African Americans and whites (Bobner, 2004). Mexican-American women are similar to whites in the USA (Espino et al. 2003). Lee (2004) suggests that elders from Hong Kong suffer significant psychological distress. Culture does not seem to predict the level of distress.

Socioeconomic status (SES) and sex are generally good predictors of psychosocial dependent variables. In the case of emotional distress associated with bowel and bladder incontinence, SES does not predict (Goode, et al. 2005). For the sex variable, both women and men suffer psychological distress, and Goode (et al. 2005) shows that men demonstrate higher levels than women (but not statistically significant). Lee (2004), using a Hong Kong sample, found men suffered significantly greater psychological distress than

women. However, both males and females had greater distress than samples that did not experience incontinence.

### **The Damage of Incontinence**

The damage associated with bladder and bowel incontinence has developed such a significant level of concern and interest, that at least four psychometric instruments have been developed to address the issue [see: Robinson & Shea, 2002]. These include:

- Urogenital Distress Inventory (UDI) for women
- Incontinence Impact Questionnaire (IIQ) for women
- Male Urogenital Distress Inventory (MUDI) for men
- Male Urinary Symptom Impact Questionnaire (MUSIQ) for men

These instruments are helpful to practitioners who need to intervene with clients who have incontinence.

The primary rationale for any type of preventative intervention is an ability to comprehend the consequences of a failure to intervene. Some consequences (or dependent variables) are obvious and discussed earlier. The hallmark of the obvious factors includes depression and anxiety. A less obvious factor includes social disengagement. Fultz and Herzog (2001) point out that when incontinence is noted among elders living in the community, they demonstrate a pattern of isolating themselves from the community. The inverse also appears. Incontinence leads to loss of social support systems such as family and friends (Corna & Cairney, 2005). Thus, we see social isolation initiated by the individual aging person or others within the shared social system. Such a phenomenon is reminiscent of the discredited Disengagement Theory originally proposed by Cumming and Henry (1961).

Social disengagement is likely to perpetuate a wide variety of problematic social and non social issues. For example, Juzba, White and Chang (2001) demonstrate that incontinent elders are significantly more likely to experience falls and fracture than elders who do not experience incontinence. Since they are socially isolated, they are more likely to not gain assistance. In addition and more tragically, Shaw (2000) cites that elders who experience incontinence are not likely to report the problem to their physician. Incontinence is too embarrassing to tell the doctor.

### **Interventions**

For the treatment of depression for an elderly client, Cognitive Behavioral Therapy (CBT) is held in high esteem (McInnis-Dittrich, 2005; Dobson, et al., 2006). Success rates are quite impressive (Fisher, et al., 2006). Tavian et al. (1994) first noted that CBT might be an effective strategy for addressing issues of emotional reactions to bowel and bladder incontinence. Later, experiments demonstrate that CBT is a statistically significant intervention for improving the quality of life among elders who are incontinent and also improves bladder

functions (Garley & Unwin, 2006). CBT and other therapies are effective in reducing the negative reactions associated with incontinence. The major question becomes, is it possible to intervene earlier in order for the reaction to incontinence (depression and anxiety) to never take place? Role playing may have the answer.

Within the context of medical intervention, a variety of preventative strategies are available to the medical staff. The research, however, suggests that nursing homes are doing a dismal job in implementing preventative strategies (see: Palmer & Johnson, 2003; Palmer & Newman, 2004). These research findings note it is less troublesome for staff to clean up after an "accident," than implementing one of the strategies to prevent bowel and bladder incontinence. Nursing home social workers are assigned the duty of resident advocate. Within this role, social workers should be offering in-service training which focuses on the importance of preventing accidents before they happen. Special emphasis should be placed on the emotional devastation associated with incontinence. The review of literature demonstrates that neither social workers nor nurses are systematically involved in preventive strategies.

### **Role Playing and Incontinence**

During a discussion of incontinence in my Gerontological Social Work course, I began by asking the questions, "What do you say to a nursing home resident who lost control of his/her bowels?" All the students had completed their interviewing course and all consistently responded to my query by replying with empathically reassuring statements. The answers were too stiff and I decided to employ a different tactic. I said, "Imagine that as you are sitting in this class, you have lost control of your bowel. The smell is permeating the classroom and all the students are acutely aware that the smell is coming from you." At that point, I repeated the empathically reassuring statements the students made a few minutes earlier and asked if those statements would help. Consistently, all students acknowledged that none of the statements would emotionally benefit them. In fact, all of them assured me that they would drop the class and avoid seeing anyone who was enrolled. A few students stated that they would drop out of college.

We began to dissect our words and derived common themes that would be more helpful in addressing the issue of incontinence. Unlike students attending a college, nursing home residents do not have the option of leaving and not returning. Four major themes emerged from the role playing experiment. 2 These include:

- make an empowerment statement
- seek medical intervention so that it won't happen again
- finding alternatives to being confronted by others who witnessed the problem
- do role reversal

Each will be discussed.

### **Make an Empowerment Statement**

According to the Strengths Perspective, empowerment and self-determination are the keys to retaining contentment with one's self. The prerequisite for articulating an empowering statement is to have a thorough knowledge of the resident's social history. Since state regulations no longer mandate comprehensive social assessments and social histories, this in-depth level of understanding is often unknown and/or incomplete in the resident's chart. In essence, the change agent utilizes a resident's difficult experiences from the past, and draws an analogy of employing past strengths to the current issue of incontinence. Acknowledging and reassuring that past problems in the resident's life were overcome leads to viewing incontinence can be viewed in the same fashion. The key to successful intervention at this point is having in-depth knowledge of the resident's past. If the change agent does not possess such knowledge and use it effectively, the resident's self esteem can worsen.

### **Seek Medical Intervention**

The simplest and most widely cited intervention in the literature is to employ the diagnosis for medication or other intervention (physical therapy) to avoid and limit the possibility of incontinence in the future. In the role playing exercise, this strategy failed miserably. We concluded that in order to be successful, the encouragement or recommendation for medical intervention must be included with an empowerment statement. Otherwise the resident is likely to regress into a childlike state. The review of literature indicates that most community elders do not and, in fact, avoid reporting incontinence to a physician. Failure to report incontinence to one's physician conceals one's frailty, but also perpetuates the disorder. When a change agent links medical intervention as part of empowering, an elder becomes the master of his/her destiny. Empowerment is the hallmark for encouraging the elder to report the incident to a physician. We hope that a physician will not make the elder feel worse.

### **Finding Alternatives to being Confronted by Others Who Witnessed the Problem**

The review of literature indicates that the fewer people who know about the incontinence, the better for the emotional state of the resident. Thus, a critical strategy is to limit the number of people who enter the room. The aides and/or orderlies who are involved need to comprehend the level of sensitivity that is required. Unlike the other strategies uncovered within the role playing exercise, this finding requires advanced planning. In-service training needs to be provided to front line workers on how to approach residents who experience incontinence. Aides and orderlies are likely to perceive incontinence as inconsequential and follow procedures for cleaning up. They need to understand that the resident does not perceive the "accident" as inconsequential, but rather as catastrophic.

### **Role Reversal**

The best strategy uncovered in the experiment is role reversal. As with the other strategies, this requires in-depth understanding of the resident's social history. We begin with the acknowledgment that incontinence is embarrassing for everyone: It is difficult to accept and stating to a resident, "don't worry about it" will only make things worse. An example of how to engage a resident in role-reversal is, "if our situations were reversed, what would you say to me to assure me that my incontinence is not a problem?" In role playing, we learned that when a person reflects on the experience of dealing with incontinence of others, their own incontinence is viewed in a more accepting manner. Residents are likely to experience a reduction of anxiety and avoid the depression that normally follows. In addition, I hypothesize that if role reversal is employed, residents will be more receptive to pursuing medical intervention to limit the possibility of incontinence in the future.

### Summary and Conclusion

The most humiliating experience an alert independent-living elder and nursing home resident faces is unpredictable bowel and bladder incontinence. For elders living independently, the event is concealed in order to avoid embarrassment and often no medical intervention is sought. The review of literature suggests that family members generally respond in an inappropriate manner. Disengagement from family members is a common outcome. In addition, elders seek disengagement from their family and others within their primary group.

For elders residing in an institutional setting, staff perceive incontinence as inconsequential and follow procedures for cleaning up. Staff, aides and orderlies do not define this even as a psychological catastrophe and respond in a nonchalant manner. The premise for following this nonchalant path appears to be ageism. Institutional staff operates under the assumption that incontinence is not emotionally problematic. That is, staffs think incontinence does not breed humiliation among elders. It does.

During the role playing experiment, we learned that even trained professional staff believe that elders (because of their age) will accept incontinence in a gracious manner because it are perceived to be a normal part of aging. Clearly, this is false. The role playing experiment reinforced this conclusion. Elders, particularly those who experience incontinence for the first time, identify the experience as regressive and humiliating. Although a wide variety of counseling theories and strategies have proved to be effective in addressing the negative emotional reaction to incontinence, our role playing experiment suggests that if a professional intervenes appropriately and immediately after the "accident," therapeutic intervention may not be needed. If it is needed, the intensity duration of intervention will be less dramatic.

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