The trajectory of tolerance for wandering-related boundary transgression: An exploration of care staff and family perceptions.

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Abstract

Purpose of the study

This study aimed to explore perceptions of the experience of living with and caring for a person with dementia who wanders and transgresses boundaries of out-of-bounds and potentially hazardous areas (wandering-related boundary transgression (BT)), from the perspective of family members and care staff.

Design and Methods

This descriptive qualitative study utilized four focus groups with care staff (n=28) and one with family members (n=4). Individual interviews (n=8) with family members were also utilized. Content analysis generated key concepts that formed the basis of the development of a theoretical understanding of the experience.

Results and implications

Care staff and families described wandering-related BT as a common dementia-related behavior in residential aged care (RAC). Drawing on the generated concepts, a complex theoretical trajectory of tolerance for BT was developed. At one end of the trajectory, BT was perceived as being beyond the control of the individual and when unwitnessed by others, having little or no impact. Tolerance for BT shifted when the BT was witnessed by others and potentially unsafe consequences for the person who wanders and their co-residents were experienced. Under such circumstances, BT was perceived as a troubling behavior in RAC that needed more effective management. Underpinning the complexity of this behavior was a constantly shifting perception of how hazardous this behavior might be, a factor that appeared to contribute to the challenges faced by families and care staff.
Key words: dementia, wandering, intrusion, aged care
Introduction

Dementia is an umbrella term referring to over 100 diseases, all of which result in progressive and incurable deterioration of cognition, behavior and function (Australian Institute of Health and Welfare, 2012). Most people with dementia will experience common behaviors, such as agitation, aggression, resistance to care, vocalizations and wandering (Purandare & Burns, 2000). Such behaviors have been conceptualized as an expression of unmet needs caused by proximal (e.g. personal, environmental and social) and background (level of cognition, general health, personality) factors (Algase et al., 1996). Of particular concern in the residential aged care (RAC) context is wandering, which is the focus of this paper.

The International Wandering Consortium recommends that wandering for research purposes be defined as:

‘A syndrome of dementia-related locomotion behavior having frequent, repetitive, temporally-disordered and/or spatially-disoriented nature that is manifested in lapping, random and/or pacing patterns, some of which are associated with eloping, eloping attempts or getting lost unless accompanied.’ (Algase, Moore, Vandeweerd, & Gavin-Dreschnack, 2007, p. 696)

Dementia-related wandering has been observed in 100% of ambulant people with dementia in RAC (Algase, Kupferschmid, Beel-Bates, & Beattie, 1997). While it has been suggested that there may be some benefits to wandering when within safe limits (Dewing, 2006), the person who wanders can experience adverse outcomes such as weight loss (Beattie, Algase, & Song, 2004), fatigue and sleep disturbance (Nelson & Algase, 2007), physical injury from falls and resident to resident violence (Cutler & Kane, 2002; Rapp & Gutzmann, 2000), becoming lost and
even death (Altus, Mathews, Xaverius, Engelman, & Nolan, 2000; Aud, 2004). Wandering can also contribute to premature placement in permanent care (Lai & Arthur, 2003). For people with dementia in RAC, factors that determine outcomes associated with wandering include who exhibits the behaviour and whether the behaviour interferes with other residents (Algase, Beel-Bates, & Beattie, 2003; Dewing, 2005). A further dimension of wandering potentially associated with adverse outcomes in the RAC environment is boundary transgression (BT).

The single published definition of wandering-related BT states that it is a ‘related behaviour of wandering characterised by locomotion into off-limit, prohibited, or hazardous areas’ (Moore et al. 2009, p.209). Potential adverse outcomes associated with BT include loss of privacy when the boundary transgressed takes the individual into the private space of other residents, or becoming lost if the boundary transgressed is an exit from the safe environment of a care facility. Despite the potentially dangerous outcomes, there is a dearth of evidence to support their association with BT and there are no evidence based guidelines specific to BT management.

In response to this gap, a two phase descriptive study was conducted to identify the characteristics of wandering-related BT using interpretive and observational evidence. This paper presents the research findings from the interpretive phase.

**Design and Methods**

To provide a forum that encouraged the sharing of experiences while broadening the scope of concepts discussed through participant dialogue, semi structured focus groups or interviews were conducted with members of each group (Sandelowski, 2000). One on one interviews were utilized as some family members preferred this format. Focus group data analysis highlighted the individual nature of the behavior of interest. We therefore posed additional probing questions
during the interviews to gain a more in-depth understanding of this phenomenon. The theoretical framework underpinning study design and analysis was the *Need-driven Dementia-Compromised Behavior* (NDB) model (Algase et al., 1996). According to this model, behavioral symptoms of dementia including wandering are conceptualized as an expression of unmet needs affected by proximal and background factors (Algase et al., 1996). Assuming that BT was a dimension of wandering, factors known to contribute to wandering (e.g. past life experiences, hobbies, interests, social and physical environment) were used to inform the development of questions used during data collection and in the interpretation of staff and family responses in the focus groups and interviews.

**Participants**

**Aged Care Facilities**

Three residential aged care facilities, offering secure dementia care in Queensland, Australia, participated in this study. Facility 1 was a large not-for-profit, denomination-affiliated, facility offering secure dementia care for 36 residents. Accommodation was provided in three cottage-style units, each with twelve single ensuite rooms. Facility 2 was a large privately owned aged care facility offering secure dementia care for 60 residents. Accommodation was predominantly two or four bed rooms with shared bathroom facilities. Facility 3 was a not-for-profit, denomination affiliated facility providing secure dementia care for 83 residents. Accommodation was in small cottage style units, each with 12 residents, or units in a multi-story building. Each unit offered single ensuite rooms.

**Dementia Care Nurses**
Twenty-eight nursing care staff in total including (Registered Nurses (RN; n=8), Enrolled Nurses (EN; n=3) (equivalent to LPN/LVN), and Assistants in Nursing (AIN; n=17) (equivalent to CAN)), who had worked at the participating facility for at least 3 months and were able to speak and understand English, participated in one of the four focus groups (Facility 1 n=7; Facility 2 n=7; Facility 3 n=14). The mean duration of employment at the participating facility was 6.97 years (SD 6.08) with a range of 20 years (1-21 years).

Family members

Twelve family members of residents with dementia who were known to wander with BT were invited to participate in either focus groups (n=4 Facility 1 only; n=1 spouse; n=3 daughters) or one-to-one semi-structured interviews (n=8; n=2 spouse; n=1 sister; n=5 daughters). Family members who had visited their relative with dementia at least monthly for the past 3 months, and were able to speak and understand English, were included. All family member participants had cared for their relative at home prior to admission and visited their relative at least weekly post-admission.

Procedure

Staff and family focus groups

Staff focus groups were conducted between September 2012 and May 2013. Facilities 1 and 3 hosted one group each and two were held in Facility 2. A family carer focus group was conducted at Facility 1 and family members from Facilities 1 and 3 participated in individual interviews. All focus groups and interviews were moderated by the first author who is experienced in focus groups and interviews. Sessions were conducted in private rooms allocated by facility management.
Following written informed consent to participate and confirming eligibility, mutually acceptable time and venue within the relevant care facility was arranged. To stimulate discussion around the behavior of interest, participants were shown a three minute video of a person with dementia wandering in an aged care facility and entering the bedrooms of other residents. The video was filmed during an earlier wandering study and released for research and education purposes. The moderator avoided use of any term to describe the behavior shown in the video in order not to bias group conversation. Participants were then asked to describe the behavior they had observed, and questions underpinned by the NDB model (Algase et al., 1996) were used to stimulate interactive discussion (Morgan, 1998). For example: background factors: "Has he/she always walked a lot?"; proximal factors: "When is he/she most likely to engage in BT?". The focus groups were audio-recorded and were of approximately 60 minutes duration. Recordings were transcribed verbatim by the first author and all identifying characteristics removed.

*Individual interviews*

Individual interviews were conducted with the relatives of residents with dementia who wandered with BT, to allow a forum in which participants felt comfortable discussing specific details of the disease trajectory. Sensitive to how the video footage may affect family members in this intimate forum, a decision was made not to show participants the video footage used during focus groups. Questions similar to those used in focus groups were posed along with additional questions specific to the trajectory of dementia and behavioral symptom development. For example: “Can you describe his/her walking habits before and after being diagnosed with dementia?” Interviews were audio recorded, conducted at mutually agreed times, in a comfortable venue recommended by the facility.
**Ethical considerations**

Ethical approval for conduct of this study was obtained from the Human Research Ethics Committee of the host university and one of the participating facilities. The other facilities accepted the university ethics approval. All participants were free to withdraw at any time. All raw data are stored in secure locations, and names/locations of participants coded to maintain anonymity.

**Analysis**

Data were analyzed using qualitative content analysis methods with an inductive approach, an appropriate method to use when investigating a phenomenon about which little information is already known (Elo & Kyngäs, 2008; Granheim & Lundman, 2003). In inductive content analysis, concepts describing the phenomenon of interest are derived from the data and can ultimately be used to develop a conceptual framework or model to add to the knowledge base concerning the phenomenon (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005).

In keeping with content analysis methodology, data were initially organized into meaningful units to identify key concepts that described the experience of caring for a person with dementia who wanders with BT. The key concepts were then interpreted to develop a model to explain this experience. The steps taken during this process followed those described by Granheim and Lundman (2003), specifically:

1. **Preparation Phase:** after the interviews were transcribed, transcriptions were read and reread to become immersed and highly familiar with content;

2. **Open coding:** headings were made in the transcript margins to describe the content;
3. Collation: Headings from margins were collated on coding sheets;

4. Concept development: Headings were interpreted and categorized, with categories grouped according to common themes;

5. Themes: Groups were named according to meaning; similar groups were collapsed to create main themes and quotes from the data were selected to represent each theme;

6. Model development: A unifying model was developed to illustrate the relationship among the main themes.

**Trustworthiness**

To ensure stringent and trustworthy interpretation of data, four steps recommended by Lincoln and Guba (1985) were adopted. Firstly **credibility** was enhanced by all steps in the analysis process being carried out by authors 1, 2, and 3 who are experienced researchers highly familiar with the phenomenon of interest, and through the use of multiple sites. Next **transferability** was achieved through clear descriptions of the sample and study protocol used. **Dependability** was enhanced by the consistent use of key questions, developed using a relevant theoretical framework, across all focus groups and interviews. Finally, **conformability** was achieved through the use of a detailed audit trail and data triangulation between the research team until there was consensus, a common method used in qualitative nursing research (Edberg, Richards, Woods, Keeley, & Davis-Quarrell, 2008; Fossum, Alexander, Göransson, Ehnfors, & Ehrenberg, 2011; Lämås, Graneheim, & Jacobsson, 2012; Wilstrand, Lindgren, Gilje, & Olofsson, 2007). To further add to the reliability of findings, throughout the analysis the team focused special attention on identification of the collective voice as distinct from the dominant voices (Smithson, 2000).
Results

BT was perceived as a common dementia-related behavior in RAC that was beyond the control of the person with dementia who wanders. Participants did not use the term ‘boundary transgression’; rather the behavior was referred to as ‘intrusion’ ‘invasion’ or simply ‘wandering’. Nonetheless, the behavior in question, here referred to as BT, was familiar to all participants, was associated with people known to wander, and most frequently manifested as intrusion into the bedroom of a co-resident. During a BT the person with dementia would interfere with and remove personal items, sit on and sleep in beds, eliminate in bathrooms and bedrooms, and walk around bedrooms. It was noted that these activities often went unnoticed by others; however, such activities could cause verbal and physical altercations when witnessed by other residents, a factor that was pivotal to the way the theoretical trajectory of tolerance for BT was ultimately constructed.

Trajectory of tolerance for BT

A clear and yet complex trajectory existed that related to the level of tolerance for BT and which varied according to experience. At one end of the tolerance trajectory, BT was perceived as a dementia behavior that was tolerated because it was beyond the control of the person who wanders due to their cognitive impairment, and would often have little or no impact on others. Yet there was an obvious and marked shift along the tolerance trajectory toward intolerance when BT was associated with outcomes that compromised safety. Three key perceptions of BT were illustrative of a tolerance trajectory: 1) aspects of BT were tolerated; 2) ambivalence for BT; and 3) aspects of BT were not tolerated (see Figure 1).
As depicted in Figure 1, the theoretical concepts that constituted the trajectory of tolerance for BT are situated along a symbolic continuum to demonstrate the changes in perceptions of BT according to experiences. Under each concept are factors that contributed to the level of tolerance and their underlying assumptions. These factors are described in detail below:

**Aspects of BT tolerated**

Three factors were associated with tolerance of BT: level of understanding about the behavior, the risk associated with the behavior, and how RAC staff were perceived to manage the behavior.

*Understanding:* Wandering-related BT was described as common, with staff and families stating they were familiar with the behavior. They demonstrated a comprehensive level of understanding about dementia and associated behaviors which were related to impaired cognition and subsequently loss of ability to differentiate between private and public space. Participants suggested that for RAC residents in the advanced stage of dementia, BTs were the consequence of geographical spaces ceasing to have meaning and the person who wanders inadvertently entering areas that were deemed ‘out of bounds’. This was perceived as being a normal part of life in RAC:

> [Regarding entering resident’s bedrooms] Yeah, it is space, it doesn’t belong to anyone. (Family)

> ... I don’t know about you, but I just tend to think it’s normal. You don’t put a label on it you just think it is normal, part of your work and... The
wandering, the going from room to room, I don’t tend to put a label on it.

(Staff)

The intrusion resulting from a BT was explained in two ways. First, that the person with dementia was unable to navigate in the unfamiliar environment of the care facility; and second, that the person who wanders was thought to be enacting a goal-directed activity such as seeking a lost personal item or familiar person, or past career related activity:

.....they've just come from their own home, some of them, or hospital and
they still remember home and they wonder where they are, they're looking
for something..... (Staff)

Well they could be looking for their wife or husband or children even (Staff)

Low risk behavior: Another factor contributing to tolerance of BT was the perceived impact (or lack thereof) of an intrusion into private space subsequent to BT. Some BTs went unnoticed by others because there were no witnesses, while other residents with advanced dementia were no longer territorial and did not appear upset by an intrusion. Under such circumstances, BT was perceived as low risk, was tolerated, and to an extent allowed to occur without interference from staff:

.....staff will come and say ‘Oh so and so is in someone's bed’. Well I'd say
‘Let's leave them there, if they're happy and contented, rather than waking
them up’ ... and making them aggressive. If it's not disturbing the other
person. (Staff)

Staff able to manage BT: The final factor contributing to tolerance for BT, referred to primarily by family members, was the perception that care staff manage BT well and that care provided in
the RAC setting was safer than families were able to provide at home. All family participants had cared for their family members with dementia prior to admission to permanent care and had experienced situations when walking had jeopardized the safety of their relative which provided them with comfort:

*But the comfortable thing about that is that they are in here, you know they are in here, they can’t get out, it’s a safe environment and it’s a big relief.*

(Family)

Family participants also reported that staff managed BT by providing assurance, comfort and safety to the recipient of BT, and reacting promptly to a BT that was disturbing to others. Further, there was a perception that staff were able to compensate for the impact of BT, for example by locating lost personal items:

*They [staff] are pretty good at coming and getting the person and moving them.* (Family)

**Ambivalence**

While staff suggested that BT was tolerated and allowed to occur without intervention, tolerance did not apply to all incidents of BT and many strategies were employed to minimize the impact of BT on others. The perceptions of BT were constantly changing suggesting ambivalence.

**Need to minimize impact of BT:** To ensure resident right to privacy was maintained, staff and families applied strategies to *prevent* a BT from occurring or to minimise the impact of a BT on others. Strategies included providing environmental cues to aid navigation, providing meaningful activity at times when BTs were anticipated to occur, and constant vigilance:
You've just got to keep an eye on them all the time and just redirect them.

(Staff)

....looking at the timing of the activities and we actually changed what some of our AINs do when they first come on in the afternoon..... when they actually got involved with the residents it [BT] became less of a problem because there were more people occupied and doing something. (Staff)

He goes into other people’s rooms; they get upset with him, touching stuff so you have to stay with him all the time. (Staff)

Family members also adopted strategies to help their relatives navigate to the correct room and to minimise impacts of BT such as losing personal items. For example, room layouts and embellishments (e.g. pictures, quilts, soft toys) were kept constant even where locations changed. The impact of lost or misplaced items was controlled by providing multiple sets of glasses and false teeth, often at considerable expense, and by keeping novel items that might stimulate curiosity out of sight or removing them altogether:

I have taken to not leaving stuff, like her hair brush and stuff that used to be on the bench. Now I put them in the cupboard in the bathroom, so the girls can still use them obviously, but (name of resident) doesn’t tend to go that far to search. Otherwise they would just disappear. (Family)

Despite the efforts of care staff to minimise the incidence and impact of BT, intrusions into private space occurred on a regular basis. To ensure the needs of all residents were met, staff reported that they would respond promptly when alerted to a BT and re-direct that person to a more suitable area. It was implied that this occurred frequently and was time consuming:
.....You just keep an eye out for what they're doing and redirect them. If I was there and saw there was obviously no-one there I would be redirecting her out of the room gently, pointing to go somewhere. (Staff)

You then redirect what you do, constantly redirect. (Staff)

Staff reported that it was not possible to anticipate all BTs nor could they anticipate which BTs would be upsetting to the BT recipient, a factor that caused them to question the effectiveness of current care strategies. They reported relying on residents (themselves cognitively impaired) to alert them, a task some residents took seriously. These discussions highlighted the serious nature of this behavior and how it affected others:

.....We've got one gentleman who warns us all the time because he's protecting another man in the room and he'll come out and he'll watch, he watches this particular person, if he comes near the room, if he can't do anything about it he'll tell him to go. He'll tell us that he's there. (Staff)

Clear threshold of tolerance: A major factor influencing the response to an intrusion associated with BT was the stage of dementia experienced by the recipient of the intrusion. How BT was addressed also depended on whether it was witnessed and if the witness was protective of the space in question. Responses could be exaggerated and also unpredictable; all participants had experienced episodes of BT that had resulted in safety being compromised. In such circumstances BT ceased to be a benign behavior - this was the point at which BT became intolerable.

She was having physical altercations with [another resident with dementia] and I actually meet with [Nurse manager] and said this is not good enough, I can’t have this, because she [Relative with dementia] was really afraid and
she did not want to live there and she was upset, and I said to [Nurse manager] this is not good enough. (Family)

.....I think ordinary wanderers they're not as much a problem, it's the violent ones because they can go and hit another resident or hit you quite out of the blue, it becomes a problem. (Staff)

It became apparent that the experience of caring for residents who wander with BT included adverse outcomes that contributed greatly to the upper end point in the tolerance trajectory, where intolerable aspects of BT became evident.

Aspects of BT are not tolerated

After crossing the threshold of tolerance, BT moved from having a benign status to being regarded as a troubling behavior, considered both high risk and difficult to manage.

Aspects of BT are high risk: BT was considered high risk when adverse outcomes were experienced. The most common outcomes associated with BT were emotional distress for the recipient of BT and physical and verbal altercations between residents:

They [resident who has had space invaded] can be frightened and nervous and if they see someone come into the room they just freak out a bit and buzz or yell or whatever. (Staff)

Confrontation is the worst part because if you have a resident who’s going into other people’s space and that person doesn’t want them in the room, you end up with confrontation. (Staff)
Staff described loss of personal items as an adverse outcome that distressed families, placing additional strain on care staff:

*Down in our unit, a lot of them have dolls or teddy bears. And sometimes you will find them down in other rooms. But it is more so the family who are upset.* (Staff)

However, family participants reported that this BT outcome was not disturbing. Only when safety was compromised was BT considered of concern:

*.....you have to let this [loss of personal items] stuff go. If she was in physical danger then I would be upset.* (Family)

An adverse outcome of BT reported by families was social isolation. A person who wanders would be at risk of being excluded from group activities because of inadequate staffing to supervise effectively or being ostracized by other residents. Both outcomes were distressing to families:

*.....then as his behavior became more challenging he was very much ostracized by the residents, and because the staff are trying to do group activities he would often get left out of the loop. Even now I see that happening.*

*He was really isolated in the other unit, and I know that. If I could feel it he must have been able to feel it – I can only describe it as negative energy..... it breaks my heart.*

The final identified adverse outcome of BT was that a person who wanders could be confused by the response of the recipient of BT to the intrusion. According to these participants, private space
ceases to have meaning for the person with severe dementia and thus the person who exhibits BT may not be aware that an intrusion has occurred. When confronted with an aggressive response to the BT, the person with dementia could become very confused:

.....Someone screaming at me to go away, ‘Why are you telling me to go away when I don’t recognise that I’ve done anything wrong’ and I don’t think she recognises ...I think it causes anxiety on both sides. (Staff)

**BT is challenging to manage:** Given the range of adverse outcomes that were associated with BT, and that carers believed it was impossible to predict when a BT would occur or if it would disturb the recipient, BT was perceived as challenging to manage. “Effective management” meant that carers would need to be ever-present. However, with limited resources and the competing needs of other residents, this was not possible. Further, as the recipient of BT could also have a cognitive impairment, as well as the person who wanders, the response to an intrusion could be unpredictable. A verbal response could quickly escalate to a physical altercation if carers did not quickly intervene:

A couple of the younger guys are a bit bothered and then they start yelling at him and then it becomes a bit verbal and sometimes it becomes a bit physical because he’s just “doing a job”. (Staff)

Usually one will walk in and the other one will yell ‘Get out’, or if they are not able to vocalise that, they will go and try and push them out. (Staff)

The complexities of dealing with BT became apparent as carers discussed day to day management and expressed conflicting perceptions of BT and associated challenges. On one hand, BT was tolerated where there was no disturbance to others and residents known to wander
were left to freely ambulate. On the other hand, this was identified as a flawed strategy as carers were not able to predict when a BT would become intolerable to others:

.....there is never enough staff because some of these people really need, if not one on one, at least more than we have especially of an afternoon and night I suppose. (Staff)

I actually think it is quite dangerous in some circumstances.....you can’t do the level of care that is needed, so I have always tried to be around more when it is needed..... (Family)

Rather than being able to manage BT (i.e. prevent it from occurring), staff resorted to reacting to BT events when adverse outcomes occurred. There was also a perception that facility management neither understood the challenges carers faced, nor provided clear policy on how BT should be managed:

All we can do is we have to watch them all the time or listen for someone to buzz because someone shouldn't be in their room or they'll yell out. That's really the only way isn't it, that we can do. (Staff 2)

They [Managers] don’t understand how hard it is, we can’t stop them going into someone’s room. We are not there to see it.” (Staff)

Staff from one facility were of the opinion that residents with dementia who wander should be physically or chemically restrained or segregated in a ‘Wanderers only’ area to minimize the potential for harm:

.....we used to tie them in chairs and let them up to go to the toilet or one of those table, chair things and me personally I can’t see anything wrong with
that because I'd rather see them like that than fall over and break a leg or hit
their head and end up in hospital and die.....(Staff)

If they can have a place that is special for the wanderers and be nursed by a
special nurse so that they stop going into other peoples rooms. (Staff)

While restraining and segregating residents was not a sanctioned first-line strategy for the care of
behaviors of dementia at this facility, the above comments highlight the frustrations these nurses
experienced, the tendency to reduce a person to a behavior and the daily challenges they faced as
they cared for people with dementia who wander. It was clear that wandering-related BT was
perceived as a complex behavior and one not currently managed adequately.

Discussion

Using the NDB Model (Algase et al., 1996) to direct data collection and frame interpretation, we
generated a conceptual explanation of the experience of caring for and living with people with
dementia who wander with BT. Our findings provide evidence for a tolerance trajectory where
the level of tolerance experienced changed according to the outcomes of an individual BT event.
Exploring the variable nature of the perceptions of BT highlighted the complexity of this
behavior and the challenges faced by carers as they attempted to manage this common and
potentially hazardous behavior in the RAC setting.

While the perceptions of BT varied according to specific examples of the behavior, there was
congruence between groups that BT was perceived as being so common that it was considered as
a normal part of life in RAC, that it was associated with wandering, and was most frequently
manifested as intrusion into the bedrooms of other residents. Further, BT was understood to be a
need driven behavior that could be triggered by the person reenacting a past life experience,
seeking the company of a loved one, or finding familiar objects to help them make sense of the unfamiliar environment of the care facility. Problems with way-finding were also considered to contribute to the occurrence of BT. Particularly for people with Alzheimer’s disease, way-finding becomes an issue early in the disease trajectory, and becomes a significant problem as the disease progresses (Passini, Rainville, Marchand, & Joanette, 1995; Reisberg et al., 2002).

With impaired way finding, the person with severe dementia will have diminished ability to locate and navigate the way to desired destinations, resulting in entry to out of bounds areas. This aspect of the behavior was accepted as being beyond the control of the person with dementia; a factor that contributed to tolerance of BT. Under such circumstances, BT was primarily allowed to occur unchecked.

A further perspective of BT shared by both staff and families and a factor that contributed to the tolerance of BT was that BT was perceived as being a consequence of the person with advanced dementia no longer being able to recognize the meaning of specific spaces: private space ceased to have meaning for them. This phenomenon can be explained by the theory of retrogenesis described by Reisberg et al. (2002). Based on Piaget’s theories of developmental stages, a person with severe dementia, such as those being cared for at the participating facilities, would have a developmental age equivalent to 15 months and would no longer have the ability to rationalize the consequences of breaking social rules such as intrusion of privacy resulting from a BT event.

When BT did not have an impact on others, it was perceived that BT events were allowed to proceed with little or no intervention from care staff. Participants in an earlier qualitative study (Harvath, 1994), suggested three factors contributed to how a behavior was perceived by caregivers: cause of the behavior, perceived control over the behavior and how problematic the behavior was to others. Behaviors that did not threaten self or others were not perceived as being
problematic (Harvath, 1994). Similar to suggestions made by this sample, behavior was tolerated without intervention if it did not impact others (Harvath, 1994). However, the shift in tolerance toward intolerance occurred when a specific BT event was disturbing to others. While some residents with dementia were no longer able to discern territory, other residents with dementia had retained memory of the meaning of private space and in some cases, a territory was defended fervently. This was associated with physically and verbally aggressive responses to the uninvited intrusion, which was a point at which the tolerance for BT shifted along the conceptual trajectory toward intolerance. BT was perceived as being an unpredictable behavior as it is was not possible to anticipate when a BT would be troubling to others or when it would have little or no impact. Under such circumstances BT was perceived as being challenging to manage, which is consistent with previous findings (Cutler & Kane, 2002; Shinoda-Tagawa et al., 2004).

While staff could explain why BT might occur, it was recognized that implementation of optimal care strategies required staff to anticipate when and where a BT would occur so that it could be prevented or at least redirected promptly. However, participants reported that due to conflicting care demands, and inadequate staff-resident ratios, this ideal was rarely possible, with staff tending to respond to a BT only after being alerted to it by others. This was perceived as a potentially hazardous situation, contributing to stress, frustration, and carer burden, all of which are associated with job dissatisfaction (Edberg et al., 2008).

However, a perspective of BT that requires consideration is the impact this behavior has on those who are unable to communicate their displeasure with having a co-resident enter their bedroom without invitation. As the need for privacy is a basic human right that does not diminish as cognition declines (Edvardsson et al 2008) it could be assumed that these residents may
experience distress even if unable to express it. The long term effects of this warrant further investigation.

Finding more effective strategies to manage BT should be a priority for future research as the level of frustration expressed by some participants was at times high. This frustration was clearly evident in discussions about the use of chemical and physical restraint as a means of managing the adverse outcomes associated with wandering and BT, a common response by carers to manage potentially hazardous behaviors (Buri & Dawson, 2000). While use of physical and chemical restraint was not a first line management strategy for behavioral symptoms at any of the participating facilities, the frank way in which participants spoke about these strategies highlighted the difficulties facing carers, the complex nature of this behavior, and their willingness to resort to these techniques as a management strategy. Using the findings that there are degrees of tolerance for BT relative to associated outcomes could help in the development of more effective management strategies that target the intolerance end while maintaining the needs and rights of all residents in care.

Conclusions

By exploring staff and family perceptions of the experience of caring for and living with a person with dementia who wanders with BT, the complexities of this behavior emerged, along with evidence that the current strategies for its management require review. Identifying who is most at risk of exhibiting this behavior as well as why and when BT is more likely to occur is key to developing effective care strategies. A validated assessment tool such as the Revised Algase Wandering Scale-Long Term Care (Algase, Beattie, Bogue, & Yao, 2001), can be used to
identify those at risk of exhibiting this behavior, which could then assist care staff to focus on where available resources would best be utilized. In addition, it is important to understand what unmet needs may be expressed through wandering and BT. The use of behavior mapping to determine possible antecedents may also reduce the incidence of BT and any associated adverse outcomes. Future studies should explore management strategies that address the concerns raised by carers regarding the care and management of people with dementia who wander with BT. Such strategies should also support wandering within safe limits while reducing the aspects of wandering that can be potentially hazardous. Reducing the incidence of wandering-related BT will arguably reduce the incidence of adverse outcomes experienced and ultimately improve quality of life for both the person who wanders and the recipients of BT.
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Figure 1: Factors contributing to the Trajectory of Tolerance for BT