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Paper Three

Wandering into the future: reconceptualising wandering?

"a natural and good thing"

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Wandering into the future: reconceptualising wandering?

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Abstract (230 approx))

There is still significant scope for improvement in knowledge on wandering in dementia and in the care of persons with dementia who wander. Although progress in research derived knowledge is evident over the last fifteen years, the current state of practice is influenced by an immature research base where the clarification of what wandering is still needs to be achieved. This is fuelled by research which to date, has framed wandering as a problem behaviour and generally starts from the premise that it needs to be prevented or severely controlled. People with dementia may think and feel differently about wandering, as will be suggested in this paper. The voices of those who have experiential expertise of dementia and wandering need to be included in the debate on wandering to influence both nursing research and practice. In regard to the practice context, it is suggested that there is little evidence to suggest that screening for wandering, assessment of wandering, person-centred and evidence based care planning and interventions or evaluation are yet the norm for older persons with dementia. Thus, these areas must be the priorities for the immediate future. Whilst at a theoretical level, there are three key issues that require attention in the future: the orientation of research on wandering including

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reconceptualising wandering to address the lack of theoretical frameworks to explain wandering, addressing the need some care settings might have with dissemination of research and recognition of the experiential expertise of older persons with dementia.

Key words: dementia, dementia related behaviour, older people, person-centred, wandering,

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Insert poem disconnected by DM Kaft (<https://www.authorsden.com>)

Disconnected

*a leaf caught in the wind
cast out by the tree
driven from the land*

adrift and alone

*tomorrow beckons
but without power
I am trapped in today*

*there is no hope
save time*

and time has stopped

Word Count 4,820 approx (excluding poems, table and references)

Introduction

This final paper is focused on reviewing knowledge about wandering; identifying gaps in current knowledge and highlighting future research and development agendas necessary for person-centred and evidence based practice with older persons who have dementia and wander or are likely to wander. Thus, it will

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summarise and build on papers one and two in this edition of the journal. Additionally, this paper will aim to be visionary, challenging and futuristic. There is an intention to take the reader beyond what is currently known about the topic and challenge existing thinking in the area. To accomplish this, the paper draws on knowledge from a number of people with dementia about how they see wandering and what they feel should be the research agenda of the future given their own lived experiences with dementia and wandering.

Accessing the knowledge or experiential expertise of people with dementia was achieved in two ways. First, people with dementia were contacted via the Dementia Advocacy Support Network International ((DASNI) <http://www.dasninternational.org>). This is an international network for people with dementia and organised by people with dementia. Exact membership probably is difficult to establish as it is essentially a virtual community. The organisers were contacted and agreed to put out a written invitation to their members, who would agree to be contacted via email to dialogue or send in their ideas about wandering for this paper, areas considered were what wandering meant, what research they would like to see and what principles of care they would want for themselves in the future should they wander. Although there are limitations accessing views of any network in terms of representativeness, this network was used because of its international basis and because it is run by and for those diagnosed with dementia. It offered an opportunity to develop an element of collaboration between nurses and persons with dementia for this paper. As Friedell a DASNI member writes, everything about dementia should include contributions from people with dementia (Friedell 2002). In total, eight people responded; seven women and one man. They all described themselves as ageing or older persons, although their chronological age was not asked for. Second, data was taken from the author's doctoral study (work in progress) which seeks to investigate wandering as it is experienced by older persons with dementia who are living in a nursing home in the UK (Dewing 2005a). In the

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study, ten participants were involved in the year long data collection. The author used conversational interviews supported by video recording of wandering alongside the older persons and observation to collect data. Some extracts from conversations with several of the participants have been selected for use in this paper. This does not mean the voice of carers is being ignored. It is well recognised that carers find wandering a nuisance, troublesome, a problem or even burdensome (Lai and Arthur 2003; Neville McMinn and Cave 2006). Indeed, carers views on wandering often parallel those of many nurses. These views have been discussed in the first and second paper.

What is already known about wandering as a problem behaviour?

Insert Picture One here

The Research Contribution

In 1999, Algase reviewed forty from a possible 108 published research studies on wandering and concluded that research on the phenomenon of wandering was ripe with opportunity for improvement. Algase identified five key points relevant to this discussion. First, conceptual clarity about the meaning of wandering was urgently needed. To classify persons with dementia as either wandering or non wandering was no longer acceptable argued Algase. She felt the emerging norm was a fuller description of the wandering behaviour. Second, studies needed to clarify the nature of dementia of the intended population as it was felt this would influence the type of wandering undertaken. This clarification is even more applicable today, given the emerging knowledge on different forms of dementia and the picture insights imaging technology is able to offer on the location and extent of neurological changes that can occur in dementia. This last comment links into Algase's third point, the importance of meshing research on

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wandering with knowledge from cognitive and neurological sciences. Interestingly, the meshing of research with other disciplines such as human geography, architectural and environmental design was not mentioned. Fourth, Algase commented on the weakness in the design of intervention studies and fifth, the obvious lack of theory development. Most research studies on wandering have not attempted to develop any theoretical descriptions or build on existing theory from other research (Synder et al 1978; Monsour Noel and Robb 1982; Dawson and Reid 1987; Young Muir-Nash & Ninos 1988; Martino-Saltzman et al 1991; Ballard et al 1991; Albert 1992; Groene 1993; Arno and Frank 1994; Goldsmith Hoeffler and Radar 1995; Holmberg 1997; Ingersoll Schroepfer and Pryce 1999; Colombo et al 2001; Price et al 2001). The exception to this has been work by Algase and colleagues (Algase et al 1995; Algase Beattie and Therrien 2001; Algase Beattie Bogue & Yao 2001) and to a lesser extent work by Cohen-Mansfield (Cohen-Mansfield et al 1997; Cohen-Mansfield and Werner 1999) and Hope and Fairburn (1990). In 2006, it is possible to say some of those opportunities have been grasped and now need refinement and some are still to be achieved.

As Algase comments in her paper in this journal, there is a growing body of research concerning dementia-related behaviours which is producing new knowledge with the potential to guide practice (Algase 2006). Due in part to this, there is a growing amount of opinion based literature on wandering mainly originating in the USA, written by gerontological nurses for gerontological nurses. The opinion literature whilst easier to digest than some of the primary research publications, tends to draw on a limited range of older research and thus may not always offer the best evidence base. Both the research and opinion literature to date, apart from a few exceptions, offers nurses and carers confirmation that wandering is generally perceived as a problem or nuisance behaviour. It also alerts nurses to, or even reinforces, the belief many nurses have, that all wandering has serious, even life threatening implications. Advocacy of the

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position that all wandering is a serious life threatening behaviour can be seen in the work of Silverstein et al (2002). This belief is reinforced by several recent studies that focus not on wandering, but on some of the outcomes of wandering such as major risk for falling, serious fracture risks with falls, elopement, and the risk of being unmanageable in a particular care setting (Fine 1983; Beattie Song and La Gore S 2005; Bennett 2005 p94). This all makes for grim reading and for many, gives a sense of hopelessness in regards to practice, particularly when put into the context of health care cultures where the stance is to eradicate risk as a means of avoiding litigation.

More optimistically, research to date has produced, a screening tool for use with people who might be at risk of wandering to identify the need for a full assessment (Dewing 2005b). Additionally, there are in existence, several typologies or classifications of wandering that enable wandering to be assessed in more depth (Hope and Fairburn 1990; Algase et al 2001; Stokes 2001). Work by Algase and others now shows that different types of wandering, which in the case of Algase are named as lapping, pacing and random may each respond better to some interventions than others. Thus interventions are not universally applicable to all wandering as the nature of wandering itself is multi faceted (Lai and Arthur 2003). Research looking at interventions has considered care-giving, subjective and non-subjective barriers, music, assistive technology, touch, walking, mealtimes, outdoor space and general occupational activities and groups and the environment as well as the effect of medication (Groene 1993; Colthorp et al 1996; Cohen-Mansfield and Werner 1999; Price et al 2001; Beattie and Algase 2002; Skovdahl et al 2003; Beattie Algase and Song 2004; Miskelly 2004; Algase 2005; Algase 2006; Sheehan Burton and Mitchell 2006; Robinson et al 2006). Findings from these studies tend to indicate some level of effectiveness with no one intervention that is therapeutic for all wandering.

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Limitations of the research to date

There are numerous and significant limitations to the research on wandering that nurses need to remind themselves of when considering how they can make use of it for practice. However, any critique must also be placed into a wider context. Although, wandering is generally acknowledged to be a problem or at best a serious challenge for nurses and carers, there is relatively little funding resource being put into the area of wandering. Thus, research in the area of wandering is not only still relatively new but also immature. Put in this context, considerable progress has been made and nurses can feel optimistic about the research that has emerged to date.

Undoubtedly, there continues to be a lack of a standardised definition of wandering for use in research and this is problematic. My own recent review of both research and opinion papers (1977 – 2005) undertaken as part of a doctoral study, showed some seventy definitions of wandering. Additionally, there is an alarming tendency for older non-empirically derived definitions still being used. Definitions developed in the United States (US) do not as yet feature widely in the UK. There may be a similar pattern between the US and other countries. Research on wandering is also limited by wandering not being clearly defined in some studies or offering several versions of a working definition so that conceptual clarity is lacking (Price et al 2001 Logsdon et al 1998). Another limitation occurs because there continues to be a blurring of concepts, where wandering gets mixed up with some of its possible outcomes, such as falls and elopement. C.J. a DASNI member (diagnosed with Alzheimer's as was his mother, now deceased) noted:

"My mother ran off and hid but I don't think she was wandering. She had asked me twice to help her die before she ran away."

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Given, not all forms of wandering lead to elopement this is misleading. The consequence of this, can be wandering, in all its forms, is seen as one entity and becomes the problem, rather than some of the possible outcomes being the problem. Thus the practice focus becomes preventing wandering because its dangerous. C.M. who has vascular dementia, diagnosed five years ago, concludes:

“Obviously, wandering can threaten a person's safety, but the wandering itself is natural, I believe people with dementia should be allowed to continue to wander in safe environments, and particularly outside.”

A further conceptual confusion occurs because wandering is sometimes subsumed into agitation; conceptualised as another problem related behaviour in most research. This is most obvious in the work of Cohen-Mansfield. (Cohen-Mansfield 1999; Cohen-Mansfield and Billig 1986; Cohen-Mansfield Marx and Rosenthal 1989). There is also some research that considers pacing, agitation, wandering, restlessness and repetitive mannerisms altogether (Neinstein and Siegal 1997). More recently, some research is indicating that there may be a relationship between certain types of wandering and different presentations of dementia. Thus research needs to both clarify wandering and dementia.

The low number of intervention studies in recent years is highlighted as a cause for concern by Algase, who has suggested for some time this is because strong intervention studies require proven or substantiated theory and sufficient pilot work to guide the intervention design and to target interventions to appropriate populations or sub-groups of wanderers and wandering behaviours. This is true, but only for certain experimental approaches to research where the interventions are specific and controlled for. Other approaches to research, such as action research, appreciative inquiry, co-operative inquiry or systematic practice development (McCormack, Manley and Garbett 2004) may be useful in

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generating and building theoretical explanations of wandering, working with practitioner's values and beliefs about wandering. As well as progressing the evidence base for practice, the agenda needs to address nurse's values and beliefs about wandering. Nurses who believe wandering to be dangerous or to be always prevented or controlled (with the seemingly positive intent of protecting the older person from harm and ensuring their safety) are not going to invest time and energy into learning about and implementing changes in this area.

Knowledge generated on the premise that wandering is a dementia related problem behaviour can and should contribute to developing greater evidence based practice. However, knowledge and consequently practice, is limited when a particular topic such as wandering (or dementia) is researched and explained in only one way. Thus the way in which wandering as a dementia related problem behaviour or for example, wandering as a natural human activity are researched and emergent understandings are offered, build up different explanatory models or theoretical frameworks (Kleinman 1981). A look through most of the research on dementia related problem behaviours shows that a bio-medical model of dementia, mainly a neuropsychiatric one is used to frame understandings of dementia and consequently any related behaviours (Downs et al 2006). These authors go on to say, in this frame of reference, there are consequences such as the neglect of social and psychological factors and the classification of all behaviours as symptoms or signs of dementia seen as a progressive brain disease. A.B. a Canadian woman and former school teacher said:

"My differences, seen in how I act, should not be seen as abnormal and unnatural but just as a sort of a diversity of what is possible in all people. As my dementia creeps into me, I am aware that it gets harder and harder to be just different and not labelled or rated on a test. Things I did before, now have become dementia related behaviours. I am wandering now, and what scares me is not wandering. I am open to this and what it might offer

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me, but that others will see this as bad and take it on as a problem for them".

Social scientists argue naturalistic sciences claims to tell us about the way things really are; that this way of theory building and explaining things is the right one. Given wide scale cultural commitment to the naturalistic sciences, this locks thinking into the positivist mode and supports the status quo that scientific truth is right. However, naturalistic science generally strips things such as wandering from their context and from how they really are. Thus the emerging generalised findings from research can mean usability is lowered – it doesn't work for me or my patients in my care setting. Another explanation might start from the position that wandering can be considered as a natural human activity and even within dementia, as an activity that is used to adapt to living with dementia (Bryden 2005 p147). Sitting still or being expected to be sitting and still (motionless) was the problem for participants in my study, not the wandering. G_ , one participant, talked about how wandering stopped her mind from changing – something she said happened if she sat still for any length of time. C. M.'s view is this:

"I have dementia myself, so I have become very interested in brain function and neuropsychology. I watch the odd things I do with interest, and I have drawn several conclusions I want to share. The first is that the brain is an amazing and determined gyroscope, or "self-righting" machine. It always works to maintain orientation in time, place, person, and PURPOSE (my own addition to the usual list). While it often fails in achieving that in a person with dementia, it never stops trying. Just as you, a healthy person, might shake off a reverie by standing, stretching and looking around, a person with dementia wanders for the same reason. He or she has a brain trying to reorient itself. This is actually a very

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*healthy adaptation to an unhealthy circumstance (neurons dying).
Wandering is actually a natural and good thing!"*

In my study, older persons with dementia who wandered had either a relaxed or focused view to their own wandering with participants moving from one approach to the other depending on contextual and personal factors. Relaxed in that they accepted wandering was something that just 'was' or more focused in feeling it was something that they had to do to achieve a particular purpose or purposes. J_, a participant in my study, who had advanced dementia, felt too much was made of wandering by those in power as a way of controlling her or people like her. In another later conversation, she said "*it must mean something because I do it naturally*". K_, wandered sometimes as way of avoiding others or skirting through the home to avoid 'bottlenecks' as he sometimes called them, in the communal areas where several people collected and where the noise level was increased, which he seemed to intensely dislike. N_, another participant said:

"wandering is, just is in my life. I live through wandering. Funny.....I I I would go like mud, no I mean, what's the word? mad.....mad if if if I was kept inside with them..... who sit like death."

Despite the limitations of research already discussed, the major limitation in the research to date, because of the dominance of the naturalistic or positivistic research in wandering research, has been the absence of the person with dementia. Although the research is about wandering and is based on the premise that wandering is a dementia related and problem behaviour it could therefore be said to be indirectly about persons with dementia. A look at the research clearly shows the person with dementia is present only in that they are a subject who is done to and the voice or contribution of the person with dementia is absent. Bond and Corner (2001) claim there are no unique methodological challenges to researching dementia, but there are several practical ones such as consent and

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and extreme forgetfulness in participants (Dewing 2002 Knight 2005). The challenge for other social constructionist approaches to research with older people who have dementia and wander is to both recognise Friedell's plea (Friedell 2002) and J. L., a DASNI member from the USA point out, that people with dementia should be listened to because "we spread our knowledge of living what cannot be learned from books" and at the same time, produce rigorous research designs and findings.

Practice Expertise

As I have already suggested, nurses need to have hopeful beliefs about wandering, what it is and its purposes as a source of motivation for wanting to address wandering. Tied in with these beliefs there needs to be a belief that the person matters (Kitwood 1993, 1997a; 1997b). That the person with dementia has certain rights and entitlements and that these do not change because of a probable diagnosis of dementia. Skilled application of knowledge in practice whether this be research generated or practical knowledge, requires knowing the person, often said to be the core of person-centred care. Person-centredness and what it means in practice is still the subject of much debate (Dewing 2004; McCormack 2004; Nolan et al 2004) and is more complex than simply knowing the person or their biography as suggested in some UK and Australian dementia care literature. Opinion literature written by gerontological nurses or carers organisations is beginning to show a more enlightened view to wandering. For example, there is often mention of wandering promoted through daily walks and the environmental factors, such as lighting and noise that may lead a person to want to leave are considered. It is carers organisations, usually via the web, who are offering a wide range of both evidence based and person-centred based advice, although in a generalised way. Knowledge on wandering needs to be drawn on, synthesised and applied sensitively according to the persons and context involved. My own review of the opinion and carer literature since 2002, has shown no increase in nurses using fuller descriptions; including

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classifications or typologies of wandering such as the Algase Wandering Scale (Algase et al 2001), or the wandering typology developed by Hope et al (1990).

During 2005-6 The UK Wandering Network (www.wanderingnetwork.co.uk) collected views on wandering of a range of practitioners (n=60) working in diverse care settings with older people who have dementia, including nurses, health care support workers, social workers and social care assistants. A method called Claims Concerns and Issues (CCIs) was used to gather the views (Guba and Lincoln 1989). Claims are favourable assertions about the topic, in this case wandering. Concerns are any unfavourable assertions about the topic. Issues are questions that reflect what any 'reasonable person' might be asking about the topic. Table One shows a summary of the CCIs. It can be seen that there were some positive assertions about wandering, indicating hopeful beliefs. These good intentions were overridden by the multiple concerns and questions nurses and other practitioners have on wandering when they face it in the context of day to day practice. It is questionable whether accessing research evidence alone will be enough to enable nurses to move beyond their concerns and associated anxiety.

Into the future: what needs to be known about wandering?

Insert Picture 2 here

Re conceptualising wandering

The future for research and practice in regards to wandering, is set within a world that is becoming more risk averse and more litigious and yet one where human rights are supposedly of increasing importance in social and legal decision making systems. It remains to be seen what these often competing tensions will mean for wandering. Nurses are often alarmed by any and all wandering and

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fearful of its consequences (see concerns and issues in Table One). This can originate from multiple sources; unconsciously acquired cultural and historical views about wandering, our own past experiences on wandering from our childhood and of others in our families and communities, our values and beliefs and knowledge base about ageing, dementia, and wandering, critical incidents with wandering from nursing and the context and culture in which nurses work. Thus, nursing energies are often put into preventing and controlling all wandering to avoid possible consequences rather than facilitating safe wandering and dealing with a few consequences.

A way to begin moving forward would be to imagine reconceptualising wandering as a natural form of activity for some if not most persons with dementia. One study participant when asked if she could say why she wandered said: *"I can't really say why – that's a hard question.....I just know I do it."* Thus for these persons, wandering could be something to be celebrated and facilitated. It is a form of human expression; freedom of movement and from this, diverse forms of connection and creativity can emerge. Wandering may improve physical health and overall wellbeing as well as quality of life and mortality. Wandering may be a way in which the person with dementia learns and engages in a more meaningful way, thus maintaining their self -identity. Reconceptualisation of wandering can lead to generating other forms of theoretical descriptions and explanations.

Obviously, such reconceptualisation would have implications for practice. The emphasis moving onto the promotion of both safe and creative wandering and only preventing wandering where it is known the risk of serious harm is too high. For example a possible implication is ensuring people were out of doors, possibility every day and as far as possible, safe wandering was facilitated. Wandering need not be something a person with dementia does as a solitary or disconnected activity, it can be accompanied not just for safety but also facilitated to be a creative experience. It may need nurses to accept wandering for some

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other persons may be a way of coping with a non sensitive dementia world and the associated neurological and mental decline, as G_ a study participant, said about not sitting down. In my research, another participant talking about wandering told me, they simply *"passed through this place as far as is possible, I don't cope.....well, if I thought I actually lived hereI stay sometimes but I don't live here"*. For these persons safe wandering might be facilitated through different interventions, or it might be that other regular activities may reduce or replace the need for wandering. There are those for whom wandering can become something they are driven to do and which can cause problems for health through malnutrition and accidental self-harm. It is these persons that prove the ultimate challenge and require the most resources of nursing and health care systems.

So, the central agenda for nurses in practice is the reconceptualisation of wandering to enable more purposeful evidence based and person-centred nursing intervention. This involves an acceptance that part of the nursing role is to facilitate safe and creative wandering. However, research oriented within the problem behaviour field needs to further research what safe wandering would look like for persons with different types of dementias at different points on the dementia scale or journey and different types of wandering.

The voice of persons with dementia

The research and practice agendas can increase usability of their work by listening to and addressing the concerns of persons with dementia. Enabling rather than preventing wandering seems to be a key message for nurses.

"I worry my home will be made so safe it will bore me. I imagine from what I know from my own work [teaching] that I will keep on learning and do this through exploring. If indoors is not exciting, well out doors might just do it!"

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I am concerned now about the risks I put myself in. But guess that won't apply later."

A.B.

"I want to be allowed to safely do so, and I'd like to be allowed to safely wander out of doors.....When I am at risk of getting lost, I'd like to be fitted with a 'Project Lifesaver' bracelet that continually broadcasts my whereabouts. If I do get lost, 'Project Lifesaver' would be able to locate me within an average thirty minutes time. I would happily trade being marked and followed electronically in exchange for my continuing ability to move about my community".

When I must be kept indoors, I'd like to have well-lighted areas to wander in, and an ever-changing array of safe items in the environment for me to discover and investigate. I'd like to be able to handle them, play with them, and possibly be able to keep them as trophies of my exploration.. Such "discovery" is inherently rewarding and essential to a positive life.

C. M.

"I've been going out practically every day of my life for one thing or another. It's just what you doA house and family doesn't run itself. I can't imagine not doing that. I might not know what I'm doing. At this point in time, if I get to that point myself, I would think I will still go out and about. I hate being cooped up". It would be easier to help me than stop me.

M.J.

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Reconceptualising wandering and recognising there are different although competing explanations for wandering is a real challenge for nurses working in health care where bio-medical explanations dominate and the majority of new research comes from the premise wandering is a dementia related problem behaviour. Nurses in practice and researchers need to find motivation to do this through valuing the experiential expertise and voices of persons with dementia (Goldsmith 1996). Current voices, as exemplified in this paper, are telling us there needs to be an agenda of research looking at benefits of wandering and how it can be enabled including through the uses of assistive technology (Miskelly 2004). As in my own research, this means working in collaboration with persons with dementia and learning about wandering in an entirely different way, based on what wandering means to persons with dementia. There are still challenges more generally, for researchers in working with older persons to achieve more meaningful participation in research (Reed Weiner and Cook 2004) as well in more specific areas like consent (Dewing 2002; Donnelly 2004; Grout 2004; Knight 2005; Dewing 2006). In research on wandering, given many persons with dementia who wander are further on into cognitive decline, the challenges will be further crystallized.

As well as generating new research, existing research may be in need of better dissemination. It has already been proposed in this paper and the previous paper, there is research on screening, assessment and some types of interventions, yet they are not being widely used in practice. Given fears associated with wandering, particularly of its consequences, dissemination can not be seen as a simple linear process of getting evidence into practice and may require action oriented forms of research and practice development to begin to both support and challenge nurses to move forward their care in ways that are context specific (Kitson et al 1998). As suggested by Neville, McMinn and Cave, (2006) in the previous paper, the priority areas are enabling nurses to recognise the value in screening and assessing wandering. To classify persons with

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dementia as either wandering or non wandering must not be a continuing norm for practice. The issues in Table One shows nurses and other practitioners have questions about wandering and their practice that could form the starting point for getting research on wandering into practice. Through working from the starting point of practitioners and through specifically addressing their questions, use of evidence based knowledge to influence care and wider aspects of practice can be achieved. Here, calculated risk taking is needed to enable transformation from a culture of care and management where wandering is seen as a problem behaviour to be prevented or severely controlled to one that for most persons with dementia facilitates safe wandering and this highlights the issue of the gerontological expertise and leadership that will be needed, not to mention a supportive organisational culture.

*“Can you seriously expect me to live – and I mean **live**, in one building or one part of a building for the remainder of my life, not being able to walk around as I wish, go out when I feel like it, feel the wind and rain on my skin and only be allowed out for special trips with a bunch of other people when someone else gives the OK? So what if I do wander or get lost? I will fight for my right to move about and fill up all the space I want to be me”*

A.B.

As research matures, the dialectic between the person, their lifestyle, psychoneurological factors of dementia, the built and natural environments both indoors and out of doors and the culture of care all point to a growing agenda of multi-professional research. Given that the importance of outdoor space to older persons is becoming clearer (Day Carreon and Stump 2000; Torrington and Chalfont 2004), subsequently the relationship between outdoor space and older persons with dementia who wander is also being highlighted and will need to be raised up the research agenda to better understand how safe and creative

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wandering out of doors can be facilitated. There are signs that research investigating way-finding and environmental design is under way (for example; <http://www.independent-eu.org/project.html>; Sheehan Burton and Mitchell 2006). The research agenda will need to be supported by a policy agenda that creates the expectation that out door space is a right and accessing out doors is part of day to day living. Once the notion of safe wandering out of doors becomes more accepted, this begins to move wandering more into the arena of a public social issue rather than just a private personal related issue, which may bring consequences for nursing practice as other agencies and the public become more engaged. This is already the position in some countries, such as the US and Canada where other agencies are more actively involved in contributing to the addressing safe and unsafe wandering in the community.

Concluding Remarks

Research that positions wandering as a dementia related problem behaviour is necessary and has contributed useful new knowledge about wandering. Theoretical explanations can also be built from this research. However, alone it is not enough. There needs to be research that offers alternative explanations of wandering. In the reconceptualising of wandering is necessary to go beyond the existing views of wandering portrayed in the much nursing and associated health care literature. What ever position is taken regarding wandering as a problem behaviour or natural activity or any other position, there needs to be more work to refine definitions of wandering and its different forms and understand what it means for persons with dementia. As this paper has shown, persons with dementia are becoming more informed and vocal about their needs and hopes. They also have a different perspective to offer and one that can't be ignored just because nursing might find it or its implications for our practice uncomfortable. The future must take account of the person with dementia's lived experiences of wandering.

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Table One

Claims
Evidence of individualised care
A positive thing to do. A normal activity Its normal
Gives good exercise when facilitated and in a supportive environment. Good exercise for the body. Good for health and well being. A form of physical activity. Reduces risks of pressure sores
Has a purpose. Can have a purpose a lot of the time
A recognised behaviour
Part of person-centred care
Has potential to challenge others to look in more depth at the person as a whole
Assertion of self Self –choice Individuality Autonomy
A form of communication A form of self expression of emotional state Releases tension and anxiety
A person's right
A way of interacting with the wider community
A way of getting away from conflict with others
We all wander

Concerns
Safety aspects Getting lost Getting mugged

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Getting knocked down
Risk management falls Abuse
Exhaustion Distress Impact on general health
Malnutrition
Impact on carers and families Relatives opinions Relatives methods of caring
Increased accident and incidents conflicts with governance systems Lack of knowledge within organisation
Lack of knowledge in staff Staff ignorance Staff feelings about wandering View that all that is needed is food and water
Not knowing if we do enough for the person
Knee jerk reactions to wandering
Conflict within families over care – different sets of values
Introducing care services
Lack of a cohesive approach No resources
Knowledge transfer across services
Legal directives arising from incident investigations
Impact on other patients in ward settings
Harming other people/public
Form of self-harm
Missing persons and police involvement
Society's attitudes to wandering Community responses
Lack of assessment tool No time to assess wandering
A form of inappropriate restraint

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Have to use restraint
Legal aspects Staff feelings about law and responsibility under the law

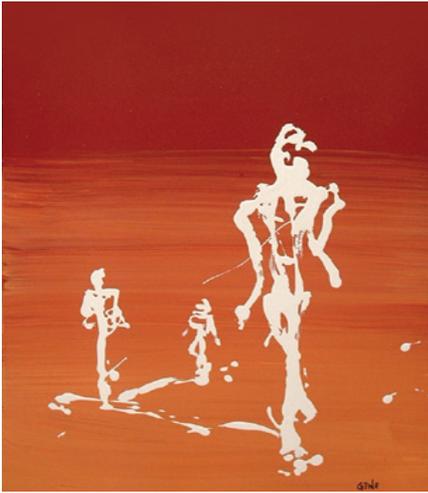
Issues
How do I balance autonomy and risk in my care setting? How do we balance Risk and Autonomy? How do we balance Autonomy and Risk?
How do I know when a person with dementia is wandering?
How can we make environments more suitable for wandering? How do we currently manage the promotion of exercise in older people who have dementia? How can we help persons with dementia who wander express their personality. How to help this wandering person express his/her personality Promotion of exercise – how do we ask how is it currently managed with older people?
How can we make sure staff have the knowledge and skills to care for people who wander?
How can we support staff who care for people who wander? How do families interpret risk of wandering?
How can we promote a more cohesive approach between settings? How do we develop a change in culture and educate our own teams? How can we develop/educate/change the culture? (Staff – Carers – Other Patients)
Do some care providers communicate the needs of people who wander better than others?
How do we de stigmatise wandering?
How do we prevent the move from labelling to 'demonising' wandering?
How do we know we're doing enough for the person who wanders?

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<p>How do we address the needs of families and carers? How do we know we have the right placement?</p>
<p>How do I balance the needs of the person who wanders with the needs of other patients? Do we have resources to meet Individual needs? Do we have resources to meet individual needs? What practical strategies do I/We need for our care context?</p>
<p>How do we balance space protection of other people wit the need of the person who explores that same space?</p>
<p>How do we change mindsets of care givers that wandering isn't a tragedy and can be managed without moving the person on?</p>
<p>How do we influence the way in which wandering and its consequences are portrayed in the media and public mind? How do we make the environment more suitable for Wandering? How do we make our environment suitable in an acute setting where the patient only has a bed and locker?</p>
<p>How do the police view wandering? How do the police view older persons with dementia</p>
<p>How do we change public perception? How do we change public view/perception? How do we educate society about older persons with dementia who wander?</p>
<p>What does assessment of wandering look like? How do we use assessment tool that are available to us? Do we have the resources to do assessment properly?</p>
<p>How is the Law interpreted by different Professionals? How is the Law on Place of Safety interpreted by different Professionals?</p>

Picture One

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Wandering

<http://www.theneighborhoodcup.com/ArtGallery/July05/Images/wandering.jpg>

Picture Two



Wandering About

http://www.makinitupasigo.com/images/gallery/wanderingabout_425.jpg

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