ABSTRACT

LATE-LIFE DISABILITY AND EXPERIENCES OF LIMINALITY

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Abstract

As we age, our perspective of time shifts increasingly towards a position which sees our lives as a 'temporary, transitional existence' (Bond, Peace, Dittman-Kohli and Westerhof 2007, p.280). Elisabeth Dittman-Kohli, (2007), writing on temporal references in the construction of self-identity, comments that as we enter old age, we begin to make more and more reference to temporal matters—the continuation of life, extending the time of independence and dealing with approaching decline and loss.

Our research into the onset of age-related frailty or disability for older people who choose or are encouraged to remain at home with care shows that doing so involves a considerable number of challenges. Ageing in place for older people dependent on formal and informal care services implies continuity and security within the comfort of home, but the experience is also one of disruption and discontinuity.

We explore this experience through the notion of liminality—that intermediate stage in a rite of passage when an individual is stripped of key aspects of their former identity, status and control over life. It is at times of transition such as this, according to Victor Turner (1969), when people become most aware of themselves and of questions of spirituality. We ask, what part does spirituality play for older people who face the disruptions caused by age-related disability? How can spirituality assist the older person negotiate these experiences of liminality as they move from independence to increasing dependence? In earlier conceptualizations of liminality, the role of guides and friends who assist in the transition into experiences of reintegration are emphasised. We ask, who are these guides, how can spirituality assist in the experiences of reintegration, and what form might this take?

Key words: ageing; disabilities; in-home care; temporality; liminality; rites of passage; spirituality.

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Introduction

Our focus in this paper is on that time of life which we identify in our forthcoming book The Age of Supported Independence, as a period of ageing characterised by frailty and increasing dependence while remaining at home. A detailed examination of this experience has allowed us to offer a critique of the policy of aging-in-place and, with relevance for this conference, understand something of the spiritual experience that is a part of this life transition. Our approach in the book, and therefore also in this paper, draws on the rites of passage framework, using this in Victor Turner's terms as a means of obtaining flashes of insight. This conceptualisation allows us to focus on the detail of the social interactions throughout that transition and the implications of these for the wellbeing of the older individual. In particular, we focus on experiences of liminality and the potential for appropriately designed care services to support the individual to negotiate these and move into a state of 'reintegration' and 'preferred identity,' however these are best defined.

The transition into ageing in place with care

Life transitions, those critical phases during which significant changes take place, continue in old age, challenging earlier perceptions of homogeneity in the later stages of life. Earlier social gerontological analyses of old age have emphasised transitions associated with the young-old, primarily with non-pathological aspects of ageing - for example, the transition from paid work to retirement and pensions and changes in residential location associated with retirement. We have sought to 'bring the body back in' to the study of the ageing experience into the place of home, significant for both older people and for policy makers, whose policies to assist frail older people are intended to maintain them at home.. This helps us to understand better the experiences of morbidity and co-morbidity that leave many people beyond the age of 80 requiring assistance to carry out the normal activities of daily living (Janlov, Hallberg and Petersson 2006, p.326).

While the ideals of home and care evoke notions of warmth, familiarity, continuity and stability, Twigg (2000) and Dalley (2000), among others, observe that the privacy of the home obscures many different situations, including loneliness, isolation, abuse, violence – all of these far from the ideal notions permeating ageing in place. The unspoken belief in remaining at home is that it is the place where the provision of support and care will best ensure wellbeing, comfort and safety. Our exploration of this time of life reveals considerable challenges, not only physical, but also social and emotional disruptions, and not only for the older individual but also for family members who become carers.

Transitions as a rite of passage

To understand that experience better, we employed the rites of passage conceptual framework developed by Van Gennep. Van Gennep's (1909) original concept of three stages, separation, liminality and reconnection, was developed to understand the different religious rituals in the cultures he studied, in particular the rituals which marked transitions between different life stages and movement from one role to another. The stages involved first, the removal of the individual from his or her former status; a suspension from normal social contact; and a readmission, reconnection or reintegration into society in a newly acquired status. This model appears to have ready applicability to understanding the change we are examining; for example, Janlov, Hallberg and Peretsson (2006) observed distinct phases in late life transitions into care that correspond with these:

> a starting point of change, through a period of instability, discontinuity, confusion and distress to a new beginning or period of stability (p.334).

The passage into in-home care is, we suggest, a major life transition, filled with complex change. But it is, as Hallman (1999, p. 221) notes, a transition 'routinely not marked with any sort of ceremony or rite.' While ceremony and ritual lend 'authority and legitimacy to the positions of particular persons' (Moore and Myerhoff 1977, p. 4), the application of the rites of passage model in the 'uncelebrated passage' (Hallman 1999, p.208) into late life frailty has been illuminating, not only because it draws our attention to the formal processes involved in accessing care, but because it offers potential to understand how this passage is structured and how we might contribute to an alternative structuring of the process. It assists in highlighting changes which tend to be taken for granted, this being evident in suggestions that 'it's all to do with getting old.' Further, it provides a structure for a detailed examination of the changing rules, roles and obligations associated with the transition to dependence and receiving care. It implies recognition of the risk of failing to complete the passage and reach a state of reconnection or reintegration, leaving an individual in a state of 'instability, discontinuity, confusion and distress.' These experiences have a profound spiritual dimension.

Separation and liminality

Applying the concept reveals the unseen separation experiences, something we see as being associated with the formalised assessment processes establishing entitlement to publicly funded home help, the effect of which is to create a potentially prolonged stage of uncertainty and anxiety.

When an older person is assessed to establish eligibility for care, the encounters with medical and allied professionals are framed by the institutional roles, professional identities and broader social structures that embody implicit power relationships. Lack of power in the assessment process and in the development of subsequent care plans challenges the sense of identity and autonomy and constructs the experience of separation.

Having a voice in these exchanges is difficult, especially when the focus is on 'embarrassing' questions such as incontinence, showering ability and personal hygiene. Such exchanges are accompanied by feelings of confusion, anxiety and anguish, 'I wasn't sure what was going on', as well as appreciation and relief. Janlov, Hallberg and Peretsson (2006, p.26) described it as 'excruciating', and 'marked by mental difficulties and strong resistance to accepting being in need of public home help.'

> Somebody came whilst I was in hospital and asked me what I had at home and so they bundled me up into an ambulance and took me home to see what I could do and what I couldn't do. … They put rails up for me and rails in the bathroom and in my bedroom beside my bed so that I could pull myself up. And they supplied me with boxes to put my chair up a bit higher. … I got terribly depressed, I'm sorry I just -- I can't cry, I have no tears. And sometimes I wanted -- I felt if only I could have a damn good howl I'd feel better, but I can't (Barrett 2005).

Interactions between the older person and the assessor are a type of institutional conversation, a discursive practice, with the effect that the person being assessed learns the philosophy and rationale of home care and the terms of accepting care. All of this is experienced in an uncertain environment in terms of the availability of and entitlement to care services. The person being assessed becomes aware of the particular needs categories, begins to see his or her situation as falling within these and leads them to construct a 'category-based identity':

> Who are you really? You become a set of ticks in boxes (p.96).
>
> It felt like an exam.
>
> [I was] worried in case I didn't qualify (Hale 2006, p.96).

Passing the assessment 'test' involves fitting within the provisions of that identity. Kingston (2000) observes that in this exchange:

> Individuals may overemphasise the degree of damage … [this being perhaps] more psychological than physical. This leads to the individual placing themselves in a lower status preferred identity, which is in effect, a reduced status identity not based on reality, but rather imposed by subtle negative societal portrayal (p.229).

The acknowledgement of change requires the older person to begin to reframe or become conscious of a changing identity. Janlov, Hallberg and Peretsson (2006 p.334) observe that, 'asking … for help seems to be a turning point, the start of a new phase in life marked by an awareness that life is nearing its end,' this point of change being captured by one of their research participants in the comment, 'The countdown has begun.'

Conceptualising this as a key part of the first stage in a rite of passage shows that individuals move through a distinct separation process, to be labelled frail and thus eligible to receive services. The assessment contains many elements found in ritual practice: a clear sense of purpose; repeated activities in a set pattern; and the subordination of personal experience to pre-established practices.

In the analysis of rituals, the 'separation' implied in the first step of the rite of passage is understood as involving the stripping of social status. Turner (1969) claims that in a rite of transition, the material possessions which mark a social identity are often removed and that people become 'invisible' as the people they used to be (p. 93). A similar experience occurs for older people facing the assessment process.

The assessment is comprehensive and the assessed person's life is laid bare before the assessor. It has important existential implications within which, as noted above, the older person is relatively powerless. Standardised assessment schedules aim to account for a person's background and living situation, the nature of current formal and informal support networks, income sources, medical history and diagnoses and current treatments, communication ability, vision and hearing, mobility, personal care ability, capacity for safe household management, and cognitive functioning.

It is like, as Aronson (2002) says, '[o]lder people are treated as bundles of expertly defined needs to be accorded priority in some standard process of resource rationing' (p. 60). It constitutes a biographical disruption as Williams (2000) avers, one that leads to a break with historic roles and identities and a narrowing of social networks, especially for the more severely frail, as unstable health and related problems of reduced mobility weaken the capacity to maintain roles, identities and networks. The post-assessment stage corresponds to a liminal phase, with conflicting emotions, improvisatory practices, and the dis-ablement which can sustain a strong sense of disconnectedness, rather than, as we tend to assume, en-ablement and re-connectedness.

The experience of liminality: spatial dimensions

The assumptions behind ageing in place imply that remaining at home, particularly in one's long-term dwelling, is an important means of accommodating physical losses and facilitating adaptive responses to new physical challenges. Home, across all cultures, is a taken-for-granted concept, generally characterised by warmth and stability, continuity, independence, security and autonomy, safety and familiarity. It implies 'doing things for yourself, doing what you want and nobody tells you what to do' (Hale 2006, p. 179). To remain at home, despite difficulties, is to show to families, friends, neighbours and others that you are capable of being independent. Dahlin-Ivanoff, Haak, Fange and Iwarsson (2007) state that:

> Home means having the freedom to come and go as one wishes and being able to do things in one's own way, and decide when and how to do things. For example, to have the freedom to decide how clean and tidy the home has to be, and how to keep things in order, all this creates feelings of home. One can close the door and be alone, or open it to friends when one wants to. Being able to decide when to lie down, if one wants a rest during the daytime, or to go to bed late, without interference from anyone else, is important (p.28).

Home arrangements express identity. But changes brought on by ageing processes and disability challenge the meanings of stability and security.

If we think about this in terms of the home as a particular space, we might see this change as 'spatial disruption.' Old age and disability require special spaces. Laws's (1997) comment that residential care represents 'new landscapes … created to house ageing bodies' (p. 25) can also relate to home care and contribution to the creation of a new personal identity. To maintain an increasingly disabled body at home requires conscious spatial decisions.

Common instances of the reordering of space in this context involve things like the re-modelling of the kitchen to allow the reaching of items; reorganizing of the downstairs part of the house into a bedrooms/living area; closing off spare rooms or rooms not accessible or in use parts of the house becoming chilly, musty and out of bounds; and using conveniently created space, such as the kitchen, re-created to provide sitting, entertaining, cooking and eating spaces. Such adaptation helps maintain control and independence, but it also makes the disability clearly visible, a defining feature of the space, a constant reminder. House modifications and visible assistive devices are material indicators of the change the older person experiences. As individuals are moment by moment confronted with physical reminders of their need for assistance, former meanings and identities associated with home are threatened or compromised.

The ageing body

This, of course, draws our attention to the body and the impact of functional loss. The sociologist May (1996) says that the ageing, lived body is the bearer of cultural and social meaning. In a world where younger bodies are more socially and culturally accepted, being confronted with one's own frail, disabled and damaged body contributes to a negative self identity and psychological angst. In circumstances of physical impairment. the body can be recognised as 'a foreign identity'.

Another aspect of the body as a bearer of social and cultural meanings is the notion that it is an expression of a moral condition. The notion of self control implies self restraint and discipline over bodily impulses and urges. 'Good' bodies are kept under control. Bodily changes are therefore interpreted as expressions of a moral condition, because, for example, it is a moral weakness, as well as degrading, to be unable to control urine flow, or a foot, or an arm; to be unable to speak or take care of oneself properly; or to work very slowly.

Loss of control of the body interrupts both the way it is ordered and the normal and acceptable forms of interaction in society. Kvigne, Kirkevold and Gjendgal (2003), describing this in terms of the experience of stroke survivors, define such loss of control as an interruption in the 'order of the body' and 'the order of interaction' (p.1307). Further, interruptions in the order of the body are magnified through the norms of social interaction. Inability to comply with those norms in the presentation of the damaged body to others, be they family, friends or general social networks, and especially in the care work situation, contribute to what Murphy (1987, p.93) has described as the 'diminution of the self'.

We might think of the extended body, a term which to describe the body when it is dependent on assistive devices, such as crutches, a walking frame or a wheelchair; the altered body, with, for example, a mastectomy or limb amputation; and the dying body. Such bodily changes affect a person's self-image and identity. Murphy (1987) conveyed this when reflecting on his loss of the full use of his legs:

> I had also lost a part of my self [note the split of my and self] ... I felt differently toward myself. I had changed in my own mind, in my self-image, and in the basic conditions of my existence (p. 85).

Between the revealing of the damaged, extended, limited and altered body to oneself, and the presentation both to self and others, is a journey of reflection, emotion, poignancy and often humour, but also often grief and self-disgust. It is a liminal process. For people with bodily disabilities, the body is a problem. It cannot be taken for granted but must be made 'the object of conscious thought' (Murphy 1987, p. 12). Am I the same person or am I a different person?

Part of this conscious thought involves the deliberate reorganization of space which, while making living at home easier, also makes frailty and disability even more visible, especially the reorganisation that occurs with the introduction of practical aids - the grab rails, ramps, raised toilet seats, and special grab poles for getting in and out of bed as well as aids for assistance to move around the home increase usable reachable space.

The emotions often accompanying such self awareness are, as Murphy (1987) says:

> '… anger, an existential anger, a pervasive bitterness at one's fate, a hoarse and futile cry of rage against fortune' (p. 106).

Becker (1993) has shown that older people living with limitations often continue to regard themselves positively and in control, although they are in need of regular help and assistance. This supports the argument of Rubinstein (1990) that, with appropriate resources, the ageing self has an enormous capacity to cope. Nevertheless, however resilient people may be, there is still the break from the self and the lifestyle prior to the onset of frailty or disability that must be negotiated.

The experience of liminality: temporal dimensions

The liminal experiences which are part of the passage into supported independence can be illuminated further by considering temporal disruptions and the various multiplicities of time which accompany the advent of government funded in-home care.

From our interviews with older people receiving in-home care in New Zealand we began, as we have said, to question the assumption that ageing in place provides for stability and continuity. One of the aspects of discontinuity was how time was experienced. While the transition into supported independence can be thought of as a broad lifecourse disruption, or, in Bury's (1982) term 'biographical disruption', closer examination indicates there are many other temporal dimensions within that broader experience. Interviews with older people demonstrate both the broad patterns of change and the more micro-level changes, such as the implication of multiple timeframes which begin to have an impact on their lives with the advent of care at home. As older people interact with service agencies they must reconcile their own slower 'disability time frames' with those of services. As Westenholz (2006) observes,

> time identities … are socially negotiated, and in the process the delineation between the individual and its environment changes (p.34).

This can contribute to the disorganized and out-of-control feelings that comprise the experience of liminality.

From the many dimensions here, one is the loss of the capacity to maintain a personal daily rhythm. Timing means personal organization, maintaining an acceptable temporal rhythm to the day, the week, or the month (Larsson, Haglund and Hagberg 2009; Haggblom-Kronlof, Hultberg, Eriksson and Sonn 2007). Daily rhythm is part of what has been laid down during the life course, and thus part of ongoing expectations. Such daily rhythms structure the organisation of the self and the home, and provide markers for the experience of the day: for example, morning is for tasks, after lunch is either siesta or leisure time, then another meal, depending on the culture. Maintaining our own daily rhythm is part of continuity and self-determination, part of keeping life on track.

These patterns of daily life are interrupted by health problems in old age. Late life ageing itself slows people down, and with frailty and disabilities, the steady pattern of everyday activities is interrupted. Taken-for-granted simple tasks need to be broken down into their constituent parts because of the inability to perform them readily, revealing facets and temporalities previously hidden in an embodied memory, and once performed effortlessly through practice, but now requiring concentrated attention.1 One of Barrett's (2005) respondents commented:

> People must think, whatever does she do all day, because I think that myself. But honestly … If you don't get up till late in the morning, and you're slow dressing, slow eating and I don't have a shower then because I can't stand solidly enough, I shake you know. So it's quite late by the time I'm sort of finished that bit. And then there are the beds, the bed to make, and the washing to do and the ironing and this sort of thing (p. 20).

Time in terms of care provision is typically organised according to the time conventions of the ordinary working day and, in the New Zealand context where directive control does not lie with the older person, its delivery is managed by an external agency. Despite the negotiation processes that are recommended, these being intended to address the power imbalance (Olaison and Cedersund 2006), the process is a significant disruption in the life course that leads to a reappraisal of identity and the experience we have described as liminality.

The experience of liminality: relational dimensions

For many such older people the disruptions caused by the onset of frailty or disability leave them in social limbo. The processes contributing to this are familiar. A combination of: physical mobility and transport problems; unstable and fluctuating health; feelings of not being able to keep up with the pace of other people; an unwillingness to inconvenience others; loss of confidence and fear of accidents or falls; an unwillingness to venture out at night; and shrinking social circles, all influence the ability to sustain community focussed networks. The resulting social isolation can lead to loneliness and depression, and points to particular challenges faced by this group of older people. Because social contact is not typically considered an "essential" activity as are visits to the doctor or shopping for groceries, people in this situation tend not to be offered and are often reluctant to ask for assistance to meet a primarily social purpose.

With policies of ageing in place, more formal care is required, partly because family members are today unable to provide the level of care to meet the increasing severity of need. New relationships are formed with needs assessors, care agencies, and care workers. These relationships are influenced by the context of expectations about how older people should behave, and the ideologies of ageing and activity that structure the policies and system of old age care (Katz 2000; Victor 2005). For the older people with whom we are concerned, interactions with family members as well as the relationships with agency coordinators and in particular the care workers are underpinned by normative views, often ageist stereotypes. Often these relationships are conducted in such a way so as to reinforce passivity and dependency in older people and undermine their autonomy and agency (Szebehely 1995, Olaison and Cedersund 2006). Aronson (1999) refers to this as a relationship that involves

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[1] Obviously different syntactic chains exist in each location. For example ablutions and brushing teeth are differentiated as people in New York don't fetch water from wells whereas many people in Kampala do.

the ‘management’ of the older person and, as such, it has particular features that require greater understanding.

Responding to these experiences of liminality

In these three domains, then, we can identify discontinuity, disruption and separation, leading to experiences of liminality. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremony. As such, their ambiguous and intermediate attributes are expressed by a rich variety of symbols in many societies that ritualize social and cultural transitions. Thus, liminality is frequently likened to death, to being in the womb, to invisibility, to darkness, to bisexuality, to the wilderness, and to an eclipse of the sun or moon. Liminars, says Victor Turner (1969), pass through a cultural realm that has few or none of the attributes of the past or of the coming state. Robert Murphy (1987), describing his experience of confronting his own disability seems to be describing this type of experience when he explained it as thus:

> ‘... the individual … [becomes] alienated from his old carefully nurtured and closely guarded sense of self by a new foreign and unwelcome identity’ (p. 109).

The rites of passage model implies a third stage of reconnection. Reconnection or reintegration means entry into the world with a new social standing or status. Liminars are made ready for this new social standing through introspection. In the third stage, the ritual subject or individual is in a relatively stable state once more, and by virtue of this has rights and obligations vis a vis others of a clearly defined and structural type; and is expected to behave in accordance with certain customary norms and ethical standards binding on incumbents of social position in a system of such positions.

This transition is in many situations defined by elaborate social rituals or ceremonies: graduation, wedding breakfasts!, and individuals are assisted in re-entering society by officials of society, by friends or by guides. But as Hallman (1999) observed, there are no ceremonies or rituals in ageing to provide positive definitions of this group of older people. The older person is now defined in terms that tend to have less social value--a ‘frail old lady’ or a ‘poor little old thing’.

How are we to respond to the challenge of facilitating the transition through the third stage of reincorporation? This is, of course, related to broader questions about what is the role of older people in society, and what is the role of those with disabilities? What is the role for those in this stage of supported independence?

According to Larry Polivka and Charles Longino jnr (2004), we need to respond in a way that supports the independence of and capacity for self direction by the older person.

> It is precisely when the individual begins to experience the erosion of freedom and agency that often comes with impairment and frailty that public policies should be designed to provide the resources needed to resist the loss of agency and allow the individual to exercise as much autonomy as possible under conditions of impairment (p. 5, supported by Tulle 2004, p. 185).

How, then, might we support as much autonomy as possible under conditions of impairment. We identify two possible courses of action. The first involves the work of home care practitioners. The second involves continuing to work to address broader exclusionary social processes that, in our ageist society, continue to see older people on the periphery.

The potential of home care

It is home care work which has become essential to supporting the goals of the policy of ageing in place and the maintenance of independence and autonomy implied in that policy. We should, therefore, attend to what might constitute reconnective care practice that facilitates the acquisiton of a ‘preferred identity’ (Charmaz 1987), socially valued roles, and which assists passage from the state of liminality. Drawing on her research and her experience in the care work sector, Hale (2006) has argued that care workers have potential to act as ‘guides’, assisting individuals as they negotiate transitions into this new life stage of supported independence. She suggests the role can be similar to that of the instructors referred to by Turner (1968) in analyses of rites of passage in pre-literate societies.

While the official policies of in-home care tend to have a narrow task-oriented focus, it is the qualitative, emotional connections in caring for another person, the listening and talking components of care which allow the recipients to ‘express who they are and to preserve their identities as something other than sick, declining persons’ (Stone 2005, p.283). Without the opportunity for this qualitative component of care, Hale (2006) observes there is a greater potential for the person to remain in the liminal stage, ‘without a foothold’ (Sacks 1991, p.77). Liminality, like grief, should, says Oliver Sacks, become a subject of understanding and sympathy. Instead, his experience of being disabled was of being ‘thrown into the further hell - the hell of communication denied,’ this occurring when his doctor failed to provide ‘genial understanding and support’ in dealing with his liminal experience which he described as ‘frightful empty images of nothingness’. Sacks is arguing that such communication and understanding provide a human ‘foothold’ during a time of limbo or ‘scotoma’.

Sacks was referring to his ‘journey of the soul’ which was separate from his medical circumstances which remained unchanged. Sack’s experience is reflected in the findings of Hale’s (2006, p.168) research. She found that receivers of care were less concerned with the performance of practical, physical care tasks than with the personal connection implicit in the care relationship, and this was captured in the comment by one care recipient who said: ‘Will they really care about me or will they just be there for the work.’ It is these inter-personal characteristics where ‘excellent care in terms of good practical skills is less appreciated by recipients than poorer physical care from more compatible workers’ (Eustis and Fischer 1991). It is the conversations which envelop the practical, physical tasks of caring that allow for the establishment of intimacy and for in-home care workers ‘to give clients their lives back and to make a difference—which is far more important to them than, say, giving a bath or a meal’ (p.283).

These relationships have the potential to preserve hope in the face of the loneliness, isolation and disorientation caused by the onset of disability and late life frailty and need for in-home care. As Stone (2005) says:

> Care is a way of fighting. It is how we fight when we are so powerless that defeat is certain, when fighting is the only thing that will preserve hope, and preserving hope is the only possible victory. It is the way we do whatever we can to make life better for the people we love, for the world, and for ourselves (p.286).

The relational, communication aspect of care work, however, sits uncomfortably alongside managerial or bureaucratic demands for accountability, impartiality, predictability and efficiency (Twigg 2000, p.162). The organisational control of funding to meet agency goals tends to restrain and limit how in-home care workers care for their clients. Again, Stone (2005) comments that when cared-for people:

> become the raw material out of which profits are made, the entrepreneur is dedicated to keeping costs down … keeping costs down means suppressing care. When care is a market good, its essence—the human component, the relationship—has to be minimised because it is an input, and efficiency requires getting the most output for the least input (p. 282).

The same dynamic plays out with publicly provided care, the pressure being accountability for the use of taxpayer funds. The organisational dimensions of the care relationship thus introduces requirements that it be counted, monitored and limited. Our challenge is to find ways of organising the delivery of care that does not undermine its potential for reconnection.

Consultative and inclusive ways of working lead to processes of negotiation that enable the care worker to give power back to the older person and reinvigorate their engagement in managing the organisation of their home and personal life. The care task in this way of working extends beyond ministering to the clinical and functional limitations of the cared-for person to include actively giving them greater autonomy. Flexibility is a key principle that should underpin practice models and extend to flexibility with budgets and task selection to allow for greater client involvement in goal setting and the development of care plans.

There needs to be a strong rehabilitative focus in supporting client direction. In many respects the care worker should work to rehabilitate the power of the older person within the domain of their own home. This method of practicing demands a high skill level, not least in the management of relationships. Home care, perceived in minimal terms as compensating for the loss of function in the older person, may have been intended as a basic domestic and personal care service, returning the cared for person to a hygienic state of living and positive routine, but it requires very much more in terms of skills and knowledge. Caring is a complex phenomenon and it tends to be the concrete, observable tasks that are used to define and describe it. Our contention is, however, that the care industry has a significant role to play in supporting the older person through this stage of liminality, reinforcing a positive identity and a reintegration or re-engagement with the wider society. These observations point to a wider set of issues. Adopting an approach that supports the autonomy of older individuals reflects a view that current cultural constructions around age and disability should be resisted, first of all within the aged care sector and more broadly in the wider society.

Valuing older people with disabilities

The second challenge to be addressed, then, is that of carving a role for older people with disabilities within our wider society. This debate is one open to discussion: what would such a role consist of?

Our suggestions of such a role, which we described as ‘Sageing within Ageing’, are in terms of understanding the process, of explaining the process, and significantly, of providing a role model for others in living with a disability. We offer some ideas here for further consideration:

i) Older people with disabilities should be visible. Such visibility is important to the extent that it ensures greater understanding of the process of disability in late life and contributes to a wider hearing of the stories of older people who become disabled.

Ii) There is a need to support a community of understanding, or, in Turner’s (1969) terms, support ‘communitas’ for older people, where they can share with each other and the wider society their issues and reflections.

iii) There is a need to facilitate opportunities for the spiritual development of older people in these situations. Atchley (2009) observes that older people have within themselves the capacity for reflection and the recognition of a spiritual process as they move towards the end of their lives. He comments that spiritual development can occur spontaneously and naturally, but there is also the possibility of being attracted to a conscious spiritual journey in the company of others. Therefore, the company of like-minded friends is important.

iv) This is linked with the need to create and maintain sustainable communities within which older people live visibly and comfortably and safely.

Such ideas imply the recognition that a person’s risk to harm is influenced by the availability of personal, family and social reserves, and the ability to access and utilize those reserves. Supporting this reserve capacity’ in spiritual terms will require practical help to assist the promulgation of a Sage role and ongoing social involvement and support.

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