Title: Rehabilitation: recognising potential and managing the transition to long-term care.

Summary

The move to a care home occurs when an older person is assessed as requiring long-term personal or nursing care. From the perspective of the older person this can be viewed as failure to attain a positive outcome following a rehabilitative process and the 'end of the line.' Yet there are many situations where older people who are admitted to care homes improve following the admission in spite of no formal rehabilitation. Whilst this suggests that rehabilitation potential can be missed and active rehabilitation should continue beyond the move, it also highlights the importance of supporting the individual through the transition from active rehabilitation to long-term care.

Introduction

For at least a decade it has been acknowledged that older people benefit from multidisciplinary assessment and rehabilitation and they are likely to require more time than younger patients to make a full recovery following acute illness or relapse in a chronic condition (Young, 1996). These notions underpinned the emphasis on active rehabilitation in the Audit Commission report, 'The way to go home' (2000), and in the implementation of the National Service Framework for Older People (2001) that focused on integrating services to promote faster recovery from illness, comprehensive assessment, provision of active therapy and treatment to provide an opportunity for recovery.

Ten years on from these reports there is an emphasis in health and social care policy on shorter hospital stay, timely discharge and avoiding unnecessary hospital admission. This may improve the efficiency of the health service; however the same drivers may expose older people to real risks of missing rehabilitation opportunities. In recognition of this situation a range of rehabilitation, enablement and intermediate services have developed (Roe et al., 2003, Glendinning et al., 2006). These often provide time-limited, outcome-focused interventions to optimise an individual's abilities to enable them to continue to live in their own home.

In this pressurised situation there are circumstances when recovery is limited and the older person is no longer able to live independently. These individuals are assessed as requiring long-term care – an outcome that can be perceived to be a failure. A failure to recover, a failure to be independent, a failure of a system that promotes independence and ageing in one's own home. This is the group of people who are the focus of this discussion – those who move to long-term care following rehabilitation. Prior to turning to an exploration of the experiences of these individuals, the rehabilitation process is considered.

The rehabilitative process

No matter what our age, when faced with physical illness, we all hope that the event will be transitory and we dream of a future in which health, home and family life will be recovered. Frank (1995) defines this aspiration as a 'restitution' narrative with the basic plot: 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (p.77).

The rehabilitation process contributes to this notion of restitution. Even the word 'rehabilitation' is infused with intent and expectation. To rehabilitate is to, 'restore to normal life by training and therapy' (*Oxford dictionary of English,* 2010). This definition has two implications. Firstly, 'normality' is based upon the usual customs that comprise our sense of 'self', (illness, being abnormal, is an entity separate from the normal 'self'). Secondly, the task of restoring normality (by overcoming disease) is achieved by the co-operation of patient and professional. Frank (1995) encapsulates this idea thus: 'I'm fine but my body is

sick, and it will be fixed soon' (p.86). Society's desire for success stories, fuelled by media examples, adds an element of heroism to rehabilitation processes that lead to restitution. In a number of narrative studies, participants are relatively upbeat and describe their illness experiences in terms of 'fighting', 'positive thinking', and 'bravery', their main allies being health professionals and advancing technology (Ezzy, 2000, Smith and Sparkes, 2005, Thomas-MacLean, 2004).

For family members too, when the acute disease phase is replaced by the rehabilitation phase, anxiety decreases due to expectations of patients' functional recovery (Visser-Meily et al., 2009). Because of these affirmative connotations, and because it is often successful, rehabilitation is fundamentally an optimistic concept, which prohibits the consideration of alternative outcomes. Disappointment is therefore deeper when it does not live up to expectations, and dreams of regaining normality are unrealised.

Poor rehabilitation outcome

Rehabilitation is a precarious process for older people due to co-morbidities, loss of confidence, or cognitive impairment issues. It is not successful for some people. For others, improvement may occur, but to a limited extent resulting in chronic illness and disability, rendering discharge home an untenable option (Arora et al., 2003, Fleming et al., 2004, Lönnroos et al., 2010). Nursing or residential care is recommended for these individuals, a proposal which can throw the older person and their family into chaos, as their dreams are trampled underfoot.

When the transition from the acute rehabilitative phase to living with chronic illness and disability occurs, the sense of failure can be immense, and blame and conflict are rife. The patient castigates him/herself for not recovering (which can contribute to depression); the family censures the patient for not trying hard enough to get well, and both blame clinicians for rejecting their suffering by failing to find a cure (Dewar and Morse, 1995, Whitehead, 2006). However, for many older people the transition to chronic illness and disability has further implications including the transition into long-term care (Schumacher et al., 2010, Shippee, 2009, Wilson, 1997).

Relocation to a care home in these circumstances can amplify negative perceptions of life in a care home. These include analogies such as 'coming to the end of the line' (Nay, 1995). Participants in Shippee's study (2009) concluded that moving into nursing home care correlated with the 'dying role'. One interviewee commented: 'They know it is all downhill. You know you are going to die' (p.423).

For families, unsuccessful rehabilitation can lead to feelings of depression and frustration as the permanency of the disability is realised (Visser-Meily et al., 2009). Feelings of grief and guilt are common, while new and unexpected challenges regarding financial management, advocacy and travel, must be faced (Gaugler et al., 2004, Majerovitz, 2007).

Rehabilitation following the move

The contrast between active rehabilitation and long-term care is most evident to the older person and their family following the move. The focus changes to long-term care and sustaining, rather than improving abilities. The notable shortfalls in the accessibility of physiotherapy, speech and language therapy and occupational therapy for care home residents intensifies the perception that hopes for recovery have been given up. For example, a health needs assessment that was undertaken in North East England (Lingard, 2011) found that residents and relatives in the Authority's homes felt that they received limited multidisciplinary support after admission.

Lack of access to services can limit the long-term improvements that can be achieved with consistent rehabilitation. Millard et al (1999), for example, identified around 40% of older people admitted to nursing homes improved following admission in spite of no formal rehabilitation. This suggests that rehabilitation potential had been missed, and raises the possibility that with some long-term rehabilitation further restoration of abilities could occur.

How staff can support residents and their families

Where no prescribed rehabilitation is available in long-term care, the nursing approach adopted can nevertheless aid both the transition process and contribute to improvements via informal rehabilitation. This is rehabilitation that occurs as a result of day-to-day activities, rather than via the input of allied health professionals (see Case Studies).
Meleis and Trangenstein (2010) believe that facilitating transition is a fundamental function of the nursing role, and suggest that transition issues should be incorporated into formal risk assessments and care planning. Documenting transition from acute to long-term settings can enhance continuity and individualisation of care, and if performed routinely, staff will begin to recognise, acknowledge and act upon patterns of responses such as despair, anxiety, depression, and deterioration in self-esteem or self-concept (Chick and Meleis, 2010) For example, Reed and Stanley (2003) studied the impact of a 'daily living plan' (DLP) on the transition process. The DLP was completed by hospital staff, and accompanied the patient to the care home at discharge. The document provided social and psychological, rather than medical information, and proved to successfully aid the transition process, as care home staff were able to pre-empt residents' concerns and needs. Views of both hospital and care home staff regarding the DLP were very positive. Unfortunately, DLP frameworks are not well established or consistently used. However, care home staff themselves can initiate transition planning by:

- Inviting potential residents/families to spend some time at the home.
- Visiting potential residents and families in hospital prior to the move.
- Requesting that NHS carers who have looked after new residents whist in hospital, accompany them during transfer in order to assist with introductions, provide care home staff with social and psychological information, and help residents to 'settle in'.
- Immediately appointing a named nurse or key worker or carer to each new resident.
- Liaising with family members to obtain details of their social history.
- Commence work on autobiographical diaries, or personal 'scrap books' in conjunction with residents and families, in which past skills and achievements are recorded, and future aspirations and goals outlined.

Thus, by focusing on psychosocial as well as physical transitions which result from failed physiological rehabilitation, care staff can re-evaluate goals of care and initiate 'questing' rather than restitution processes.

While rehabilitation strategies are primarily medical model interventions that reduce impairment, and promote independence, 'questing' is based upon the social model of disability and values autonomy over independence (Abberley, 1987). This philosophy promotes acceptance of impairment, and focuses on changing social and attitudinal environments. The 'quest' approach views illness as an impetus for developing and modifying aspirations, and an opportunity to explore new possibilities and identities, rather than concentrating on remedy and restoration (Frank, 1995).

Questing is a difficult concept to embrace, particularly for older people and in the light of failed rehabilitation. However, individuals' hopes and goals are largely influenced by the attitudes, advice and practices of their immediate support network (Nelson, 2001, Smith and Sparkes, 2005, Howard, 2006). If staff revise care objectives to include 'quest' processes, then residents are more likely to envisage and strive towards alternative, achievable dreams. Quest activities include focusing on what individuals can do (as opposed to what they cannot do), and ensuring skills are recognised and regularly employed to maximise improvement

potential. Individuals should be encouraged to explore new interests and pursue their ideas. Staff can provide resources, referrals and opportunities to bring residents ideas to fruition. Staff can also assist families to retain involvement in residents' care. This may involve including relatives in personal care activities, or providing information and introductions regarding relevant community projects, committees, and social recreational activities (See Case Studies).

In addition to the approach to care, the environment can be supportive to the individual experiencing the transition from rehabilitation to long-term care. Chick and Meleis (2010) state that transition within a consistent, stable environment is less perceptible and therefore less stressful. In some initiatives, NHS funded rehabilitation units and privately/socially funded long-term care provisions are located within one building, and utilise the same facilities, resources and staff. Individuals requiring permanent care are therefore already familiar with the environment. Social contacts and relationships are already established between the older person and staff; patients and families have had the opportunity to witness care, participate in activities, and thus become aware that long-term care is not necessarily synonymous with end-of-life. In addition, staff working within these settings are accustomed to both rehabilitation and long term care roles, enabling residents to benefit from both skill sets.

Conclusion

The move from active rehabilitation services to long-term care requires considerable adjustment for the older person. Staff need to be aware that this can be a traumatic experience. They can support the new resident to adjust to the move and to recreate a life that is worth living thus optimising their abilities and fulfilling new aspirations.

Key messages

- The transition from active phase of rehabilitation to long-term care can be traumatic for the older person and their family
- The potential of older people can be missed if rehabilitation does not continue following the move to a care home
- Staff have a key role in supporting residents to establish long-term goals and re-shaping personal aspirations through a 'Questing' approach to care

Informal Rehabilitation utilising 'Questing'.
Case Study 1: Jane Jones

Jane Jones is a 70 year old unmarried woman who has always lived alone. However, she has regular contact with her widowed sister Jean. The sisters have a common interest in art and frequently visit local art galleries and craft fairs together. They are both skilled at needlework.

Recently, Jane suffered a series of strokes. As a result, she is unable to weight bear, or use her right arm. Her left arm and hand are also weaker. In addition, Jane's speech and cognitive ability have been affected. She is also incontinent of urine.

Once discharged from formal rehabilitation services, Jane is able to mobilise using a wheelchair. She is also able to eat independently, as well as being able to participate in personal care activities with the aid of nurses and care assistants. Her speech and cognition have also improved.

After the completion of health and social assessments, it was agreed by Jane, Jean and the Multi Disciplinary Team, that Jane would be unable to manage at home, and therefore requires permanent nursing care.

On admission to the nursing home, Jane was initially quiet and withdrawn. She was reluctant to leave her room, or engage with other residents. She informed both her sister and the home's staff that she 'no longer wished to live', because she was unable to carry on her old pursuits. Jean was also upset as she felt both unable to help her sister, and bereft of her company.

Jane's named nurse, Kate, organised a number of informal meetings with Jane and Jean so they could discuss Jane's concerns with a view to designing and implementing a 'questing plan'. The following schemes were initiated:

- Maintaining and improving strength and co-ordination in Jane's left hand.
- Practising and improving speech.
- Improving concentration and cognitive skills.
- Maintaining and enabling social skills.
- Improving continence.
- Improving mood and emotional health.
- Improving confidence.

Informal Rehabilitation utilising 'Questing'.
Case Study 2: George Smith

George Smith is a 76 year old widower. He was a farmer until his retirement at the age of 70 when he sold his farm and moved into a cottage in a small rural village in the north of England. George has one son, Keith, who is an agricultural consultant based in London. Keith's job involves a degree of international work, so he spends much of his time abroad. George has always been a keen horseman, and since his retirement he has helped out at a local livery yard breaking and riding horses. He has also been able to indulge his passion for sports gunmanship. When Keith visits George, they go riding and shooting together.

Recently, George suffered a stroke resulting in left hemiplegia, and some cognitive impairment leading to short-term memory loss. During his hospital stay, George had 2 falls, and although he was not injured, his confidence has diminished and he is often anxious.

After a period of formal rehabilitation, George is able to walk short distances with the aid of a stick. However, when George is stressed, his balance deteriorates, leading to further anxiety. After conferring with his son, George decides he would struggle to manage at home, and agrees to move into permanent residential care. Keith. However feels guilty and worried about his father. He feels he has abandoned him.

On admission to the care home, George showed signs of

By utilising a ‘questing plan’, George is able to envisage a new future, and move forward. George realises that while his changed circumstances prevent him from pursuing his old interests, they also provide opportunities to explore new, achievable activities. As well as regular fishing trips facilitated by the home, George goes fishing with Keith during his visits.

The informal rehabilitation that these activities provide includes:

- Maintaining and improving mobility.
- Maintaining and improving upper body strength and co-ordination

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