Working with older people and their families

edited by
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Foreword

In 1997, as part of the extensive Research and Development programme evaluating education and practice developments, the Board commissioned a study, the Longitudinal Evaluation of the Educational Preparation of Nurses in the Care of Older People. The need to undertake the research arose from a range of sources including previous research completed within the Research and Development strategy, policies which acknowledge the increasing numbers of older people in society and the range and complexity of their needs. The Board is committed to the development of evidence-based professional knowledge to enable nurses working within the multi-professional team to identify and meet the health and social needs of this important client group.

The longitudinal study is due to be completed in summer 2001 and the emergent findings in the final report will be considered in relation to educational policy and practice development.

The Board recognizes the importance of disseminating research findings and is delighted to support the publication of this very informative text, which was presented to the Board in summer 2000. It is commended to all involved in the care of older people and their families including carers, policy makers, managers, educationalists and practitioners in the health professions. Understanding the issues addressed in this book should do much to enhance the quality of practice in the care of older people.

Professor Ron De Witt
Chairman of the Board

Professor Jeff Thompson
Chairman of Research and Development
at the English National Board
Recognising lay knowledge as having an equal part to play in health care decision-making with expert knowledge, provides fundamental challenges to health care professionals.

(Barnes 1999: 25)

The nature of health and social care is changing in fundamental ways. Fuelled by an increasingly well-informed public, expectations of services are rising and ‘blind trust’ in professional expertise is slowly being eroded, with users and carers actively seeking more equal status (Barnes 1999). While scientific and technological advances increase therapeutic potential, they simultaneously raise tensions, both financial and ethical, about access to treatment and the relative balance between care and cure (Dargie et al. 1999). One of the most acute expressions of such tensions arises when the rights and expectations of older people, and particularly vulnerable older people, are considered. Although notions of partnership pervade policy discourse, there is mounting evidence that older people and their carers often remain marginal figures in important decisions about their treatment and care (Audit Commission 1997; Health Advisory Service (HAS) 2000 1998). Indeed recent media attention and consequent public concern about poor standards of care for older people has been such as to cause a significant reorientation of policy, with the new benchmark of quality in the National Health Service (NHS), the National Service Frameworks (NSF) shifting their focus away from ‘patients with particular conditions’ (Department of Health 1998a) towards more heterogeneous groups such as older people.

The UK government, we are told, will not tolerate substandard care for older people and for the first time the NSF will set national standards which, in moving towards evidence-based care, will recognize that the views and experiences of older people and their carers are an essential part of such evidence (Hutton 1999).

If this is to occur there has to be a dialogue between the abstract
knowledge of professionals and the situated knowledge of those on the receiving end of care and services (Barnes 1999). Advancing this dialogue is one of the primary aims of this book. It emerges as the product of the first phase of the AGEIN (Advancing Gerontological Education in Nursing) project, a three and a half year longitudinal study funded by the English National Board for Nursing, Midwifery and Health Visiting. The project itself is evidence of the Board’s continuing concern about standards of care for older people and its commitment to advance practice by articulating more clearly the knowledge, skills and attitudes essential to quality care. The ultimate aim is ambitious, to identify an epistemology of practice for those involved in the care of older people.

Such an aim should not be construed as tribal, about protecting or advancing vested professional interests. In tendering for the project we the editors, and all of those contributing to this volume, stated our belief that any epistemology of practice that might emerge should be capable of uniting rather than further distancing disciplines. Most importantly, it should help to reconcile power differentials between professionals and older people and their carers by providing a shared and reciprocal sense of direction and purpose. We therefore adopted a very broad approach to the identification of relevant literature sources (see Appendix).

We considered this essential as recent years have seen the emergence of a number of tensions: within gerontology as a discipline; within policy initiatives designed to address the needs of an ageing society; and among practitioners interested in meeting the needs of older people and their family carers in an holistic but cost-effective manner. Many of these tensions are characterized by a growing interest in the quality of life of older people, particularly the ‘oldest old’ and how services can maintain a good quality of life in the face of increasing demands and finite resources.

Partnership and empowerment are key themes in the policy rhetoric and coincidentally a number of professions are talking of new ‘cultures of care’ which are more person-centred. The aim is to educate a generation of ‘expert’ practitioners who are able to blend tacit and propositional knowledge in creating new ways of working. Yet paradoxically there is growing concern that educational preparation, particularly within health care disciplines, pays scant attention to the needs of older people and that an acute orientation reinforces negative attitudes and predisposes students towards work in more hi-tech areas of care.

To date, gerontology had done relatively little to address such deficits. Bengston et al. (1997) suggest that as a discipline gerontology is ‘data rich but theory poor’ and that there has been little effort to provide a synthesis in key areas. Moreover, they argue that the situation is compounded by the failure to highlight the implications of existing theory for policy and practice. It is precisely these issues that this book seeks to address.

Our primary focus is on factors affecting the quality of life of categories of vulnerable older people and their carers in the context of care delivery in a range of environments. We believe that services will not improve until
care, as opposed to cure, is accorded greater value and status and more attention is given to those factors promoting job satisfaction and morale among practitioners.

Care therefore lies at the heart of this book. This reflects a long-standing interest of the contributors in an improved understanding of the nature of care and the interface between those giving and receiving care and between formal and family caring systems. Notwithstanding the diverse and contested nature of care, there is a growing consensus that its complexities cannot be fully appreciated unless due account is taken of the perspectives of all those concerned. Therefore in addition to affording greater recognition to the contribution of those requiring care and support (Nolan et al. 1996a), Davies (1998) argues that there is a need to transcend the dichotomies between caregiving (family care), care work (that provided by paid unqualified staff) and professional care. Bringing competence and caring into a new alignment is, she believes, one of the most ‘urgent intellectual tasks’ for the new century. This book is our own, albeit limited and incomplete, attempt to suggest how such a new alignment might be achieved.

It begins with two chapters intended to ‘set the scene’. The first provides a broad overview of issues influencing the quality of life and quality of care for older people and their carers. By integrating these outcome dimensions a framework is introduced comprising six ‘senses’: a sense of security, continuity, belonging, purpose, fulfilment and significance. It is suggested that these senses provide a potential mechanism for capturing important perceptual and subjective dimensions of ‘good care’ for both older people and staff. The second chapter explores the notion of ‘expertise’ and seeks to redefine lay and professional relationships. It highlights different types of knowledge and the emergence of the concept of person-centred care, and the tensions this raises between technical and interpersonal competence.

The subsequent six chapters take a more focused approach and consider the literature on the needs of older people and their carers in six relatively discrete areas. These are acute and rehabilitative care, community care, continuing care, palliative care, mental health in older age and learning disability in older age. The final chapter is a synthesis of the main themes emerging throughout the book. The initial six senses are revisited in the light of the literature and empirical evidence and a more detailed exposition is provided. The senses framework is offered for more rigorous empirical testing and conceptual scrutiny with the hope being that it will offer a mechanism via which to achieve, at least in part, the goal of person-centred care for older people, family and formal carers.
Quality of life, quality of care

Mike Nolan, Sue Davies and Gordon Grant

The findings reported at this congress led us to a profound concern for the future prospects for quality of life of older people everywhere.

(International Association of Gerontology 1998)

The drive to place quality at the heart of the NHS is not about ticking checklists – it is about changing thinking.

(Department of Health 1998a)

Community care policy in the UK reflects contradictory aspirations (simultaneously) promoting resource efficiency and cost effectiveness while advocating a process of needs-led assessment, which provides time for individuals to make their own decisions (Wistow 1995). Nowhere are these tensions more apparent than when the needs of older people, and particularly frail and vulnerable older people, are considered. As there are few precise objectives for community care of older people policy is based primarily on the language of general principles (Henwood 1992). Therefore although higher order concepts such as dignity, independence and autonomy are widely accepted as inherently good, what these actually mean and how they can realistically be achieved is far from clear (Williamson 1992), as such values are ‘simple in their expression but highly complex in their translation into behaviour and practice’ (Hughes 1995). This complexity is reflected in White Papers on health and social services (Department of Health 1997a, 1998b) and national priorities in both these areas (Department of Health 1998c) which place considerable emphasis on promoting independence and creating a system of ‘integrated care’ so as to break down the ‘Berlin Wall’ between various service agencies, and ensure that users and carers become genuine partners. The intention is to focus on what ‘really counts’ for patients (Department of Health 1997a) so that measures of quality and outcome genuinely reflect
the priorities of individuals, their carers and families (Department of Health 1998b). While it is claimed that such policies make sense in both ‘human and financial terms’ (Department of Health 1998c) more critical analysis suggests that the motivation is economic, fuelled by the desire to relieve pressure on acute and long-term care beds (Hanford et al. 1999). Once again therefore current rhetoric reflects the ‘language of general principles’ and the tensions between humanistic and financial incentives noted by Wistow (1995) are still apparent, indeed exacerbated.

The purpose of this chapter is to explore the above tensions in greater detail and to begin to suggest ways in which general principles might more readily inform policy and practice. The primary focus is on issues to do with the quality of life and quality of care for frail older people. The chapter highlights differences between the perspectives of service providers and older people and outlines a framework which potentially helps to achieve greater convergence.

Outcomes of care for older people

Globally the primary objective of care programmes for older people is to maintain the individual in their chosen environment, most usually their own home (International Association of Gerontology 1998). While some have challenged the taken-for-granted superiority of living in the community (Baldwin et al. 1993) there is little doubt that for most people this is their preferred option (Victor 1997). Questions have been raised about the quality of life of frail older people living in the community, and the enrichments or services necessary to promote this (Lawton et al. 1995).

Kane (1999) laments the fact that at the beginning of the twenty-first century there is still no clear vision on the responsibilities for, or the potentialities of, home care, beyond keeping someone at home. In order to advance thinking in this area she outlines a range of therapeutic and compensatory interventions and their associated outcomes in a number of domains. Although her analysis is cast primarily in the context of the privately funded system of health and social care operating in the United States her arguments have wider application, particularly in relation to the more subjective and less tangible outcomes. Kane (1999) poses difficult questions about which outcomes are achievable and can be paid for, suggesting that attention is given only to areas such as well-being, autonomy and the promotion of a meaningful life when resources permit. She sees this latter issue as particularly important, believing that there is growing evidence that too many older people, including those living in their own homes, experience a sense of a life not worthwhile; a perception that their value as people has ended.

If the situation is to improve, there is, according to Minkler (1996), a need to adopt a new perspective based on a ‘critical gerontology’, a value committed approach that seeks not only to understand social ageing but
also to change it for the better. Following a similar logic (Kivnick and Murray 1997) contend that services must move beyond remediation and compensation, so that gerontological practice is concerned with identifying, utilizing and enhancing clients’ assets. A particular challenge is to transcend traditional welfare structures based on dependency and to address the ‘existential doubts’ that accompany ageing, in order to help older people maintain or construct a viable identity (Phillipson and Biggs 1998).

Minkler (1996), while acknowledging the importance of structural influences on the ageing process, stresses the need to consider its ‘human face’ and to reflect upon ‘existential meaning in the last stages of life’. In other words, those aspects that help to reinforce a sense of identity and purpose in later life. She questions the largely uncritical acceptance of aims such as promoting independence and successful ageing, arguing that this leads to the stigmatization and disempowerment of those who do not meet the ‘criteria’ of success. In these ‘politically mean-spirited times’ she contends that empowerment should be adopted as the unifying concept in critical gerontology, with an attendant focus on interdependence rather than independence and ‘power with’ as opposed to ‘power over’ (Minkler 1996).

Others too promote the concept of empowerment (Williamson 1992; Wistow 1995; Clark 1996) and the adoption of a values-based approach to service design, delivery and evaluation (Hughes 1995). While such calls are consistent with the current policy rhetoric they bring into sharp relief the tensions between the desire for quality services to reflect a user perspective and the simultaneous push towards the standardization of outcome measures in health and social care (Sinclair and Dickinson 1998). As Sinclair and Dickinson (1998) note, quality improvement and clinical effectiveness are integrating forces, particularly in the NHS; although there is now more emphasis on the aspirations of older people, the outcome measures most frequently adopted, that is physical functioning and length of hospital stay, remain methodologically and conceptually limited. Therefore while the rhetoric of both politicians and service providers is to ‘put the person first’, most outcome measures rarely achieve this, raising fundamental questions about ‘outcomes for whom’ (Bond 1997).

This issue has perplexed providers of health and social care for older people, particularly frail older people, for some time. Challis (1981), for example, identified seven outcome domains for community-based social services for older people: nurturance; compensation for disability; maintenance of independence; morale; social integration; improved family relations; and community development. These domains reflect the need to include both objective and subjective dimensions as highlighted in Kane’s (1999) more recent analysis. As Kane (1999) contends, if a critical gaze is applied there is little doubt that, in reality, it is the objective and readily measurable indicators that predominate.
The situation is perhaps even more confused in health care, especially for individuals with chronic illness, where cure is not an appropriate goal (Clark 1996). Tensions about the appropriate goals of care have been apparent since the earliest days of geriatric medicine. There was recognition that the heroic model was not appropriate (Clark 1995) and a functional model in which improvements in physical functioning became the main criteria of success was substituted (Wilkin and Hughes 1986). Therefore despite claims to an holistic approach practice was still dominated by a biomedical construction of ageing (Reed and Watson 1994; Koch and Webb 1996). This had a particularly pernicious impact in long-term care settings where the continued application of a curative or restorative model (Reed and Bond 1991) led to a failure to specify valued goals, so that patients were subjected to ‘aimless residual care’ (Evers 1991).

The above dilemmas are currently exacerbated by the rising numbers of frail older people living in the community (Victor 1997) and the increased prevalence of chronic illness (Clark 1995). This has led some to call for a paradigm shift in the way that the goals and outcomes of care for older people are conceptualized (Bond 1997), so that the main focus is on quality of life (O’Boyle 1997). Quality of life is viewed as a potentially unifying concept for care services (Renwick et al. 1996) and the way in which it is defined and measured is therefore of considerable significance.

**Quality of life**

With greater recognition that prolonging life at any cost is less important than the quality of life lived (Clark 1995), increasing attention has been given to the way in which quality of life is defined and measured (Brown et al. 1996a; Renwick et al. 1996; Haas 1999). Indeed quality of life is currently one of the most important outcomes of health and social care, particularly when cure is no longer an option (Martlew 1996; O’Boyle 1997).

While Renwick et al. (1996) suggest that quality of life may provide a potentially unifying concept, there is little consensus as to a definition (Bowling 1995b; Farquhar 1995; Hanestad 1996; Haas 1999). Although there is widespread agreement that the concept is multidimensional, and comprises both objective and subjective components (Farquhar 1995; Woodend et al. 1997; O’Boyle 1997; Powell-Lawton 1997; Haas 1999) existing measures possess limited validity, particularly when applied to older people. Current approaches exhibit a youthful bias, with the content of most scales being dominated by items of questionable relevance to older people (Stoats et al. 1993; O’Boyle 1997; Reed and Clarke 1999a). To compound matters objective criteria figure more prominently than subjective perceptions in most existing measures (Farquhar 1995), usually reflecting taken-for-granted notions of autonomy and independence, operationalized primarily using indices of physical function. Autonomy, it is suggested, has replaced dependence as the main concept underpinning
health and social care (Williamson 1992), with some arguing that it currently carries more weight than it can bear (Carson 1995). Autonomy and independence primarily reflect the essential ethic of the American way of life (Trieschmann 1988) with self-reliance being ‘lionized’ (Kivnick and Murray 1997) by a society that values ‘doing’ rather than ‘being’ (Charmaz 1983). Clark (1995) argues that while most authors endorse the importance of quality of life the present overriding emphasis on independence, measured using proxy indicators of Activities of Daily Living (ADL), has to be challenged.

Unfortunately, the importance accorded to ADL is so deeply entrenched that the assumptions upon which such a model is based are rarely recognized, let alone challenged, with Porter (1995) contending that an ADL research tradition dominates the consideration of outcome measurement, especially in health care. Thus a professionally derived conceptualization of quality of life, based primarily on objective criteria, has hegemony (Farquhar 1995; Wistow 1995; O’Boyle 1997; Haas 1999) and if subjective criteria are included they usually reflect the perceptions of researchers (Day and Jankey 1996), with patients’ or carers’ views rarely being adequately addressed (Chesson et al. 1996). The dominance of a professional perspective is a matter of considerable concern as there are often ‘striking discrepancies’ between the views of professionals and those of disabled people (Loew and Rapin 1994; O’Boyle 1997; Livingston et al. 1998; Reed and Clarke 1999a), who frequently hold differing value maps and fundamental perceptions (Clark 1995, 1996). Consequently, as Peters (1995) notes, professionals and users often have a significantly different understanding of the phenomena that initially brought them together.

Discontent with existing approaches to measuring quality of life, which ‘lose the human being’ (Kivnick and Murray 1997), have led for calls to move beyond ‘statistical sophistication’ (Bowling 1995a) towards a model which sees the older person as a ‘sentient partner’ (O’Boyle 1997), and the subject rather than the object of care (Williamson 1992). Incorporating a meaningful subjective element into quality of life measures is a major methodological and conceptual challenge (O’Boyle 1997), as the success of services depend substantially on our understanding of how frailty is perceived and understood by patients and caregivers (Schulz and Williamson 1993).

Numerous authors therefore argue that the fundamental questions in relation to older people are ‘what gives life value and meaning?’ (Loew and Rapin 1994; Clark 1995, 1996; Hanestad 1996; Prager 1997) and ‘what is required to sustain, or if necessary reconstruct, a serviceable sense of self?’ (Charmaz 1983; Powell-Lawton, 1997). As noted earlier, existential questions such as ‘who am I’ are particularly important to a better understanding of later life (Minkler 1996; Phillipson and Biggs 1998). Methodologically this requires a phenomenological approach (Stoats et al. 1993; Bowling 1995b; O’Boyle 1997) in order to capture an emic, or insider, view (Peters 1995; Johnson and Barer 1997). Moreover,
for older people in particular, quality of life indicators should incorporate a biographical and temporal dimension (Clark 1996) that provides a sense of past, present and future (O’Boyle 1997). This shifts the focus away from an almost exclusively problem orientated model towards a more balanced approach that recognizes both the limitations and potential that ageing presents (Clark 1995; Fontana 1995; Kivnick and Murray 1997; Wenger 1997; Thorne and Paterson 1998). Only in this way will a more sophisticated understanding of what comprises ‘successful ageing’ emerge (Baltes and Carstensen 1996; Wenger 1997).

Consequently theoretical development is essential to advancing gerontology in general and quality of life in older age in particular, as current approaches to quality of life usually reflect powerful vested interests rather than sound theory (Bond 1997). Indeed quality of life measures are often a-theoretical (Clark 1995; Hughes 1995; Renwick and Brown 1996; O’Boyle 1997); while this is partly due to the lack of consensus on development in old age (Hughes 1995; Bengston et al. 1997) others argue that a clearer understanding of what constitutes a good quality of life in older people could be attained if more use were made of existing theories (Hughes 1995; O’Boyle 1997; Wenger 1997).

Therorizing quality of life and successful ageing

Coleman (1997), one of the foremost psychologists of ageing in the UK, believes that to date too little attention has been given to the psychology of ageing and suggests four areas in which further work is needed. These are:

- recognition of the importance of a lifespan perspective
- a consideration of development in later life with a focus on ‘ordinary’ as opposed to ‘exceptional’ ageing
- more study of the individual life, moving away from what is statistically ‘normal’
- the need to achieve a balance between the third and fourth ages in order to appreciate the existential challenges of frailty.

Coleman suggests that the continued failure to address this latter issue perpetuates a profound failure of meaning. Therefore while early studies on ageing painted a nihilistic picture, currently too much emphasis is placed on people who age exceptionally well (Minkler 1996; Coleman 1997; Thorne and Paterson 1998). For example, Thorne and Paterson (1998), in summarizing trends in research into chronic illness during the 1980s and 1990s, chart the move away from an illness as burden model towards a more positive perception. They caution that the image of the cheerful, existentially transformed person with chronic illness does not necessarily reflect reality for most people.

Nevertheless there is an emerging body of work which suggests that
despite the increasing frailty associated with advanced older age, individuals generally manage to sustain a positive view of their quality of life. Such findings are said to represent an ‘empirical puzzle’ (Brändstätter and Greve 1994), being described as ‘counterintuitive’ (Johnson and Barer 1997) and therefore in need of further exploration. Authors such as Minkler (1996) argue that there is a need to better understand ‘meaning’ in later life and that to do so we must transcend the present preoccupation with the state of the body. Only in this way will we learn to appreciate how older people adapt positively to the limitations that ageing inevitably imposes (Loew and Rapin 1994; O’Boyle 1997; Wenger 1997). A number of recent theories offer potential explanations and while each asserts the superiority of its own position there is nevertheless an underlying uniformity suggestive of an emerging consensus. A number of these theories are outlined briefly below.

Coleman (1997) believes that one of the most elegant psychological theories of successful ageing is that proposed by Brändstätter and Greve (1994). Based on considerable empirical work these authors argue that an adequate account of how people maintain a sense of personal continuity and meaning in the face of the multiple losses that often accompany ageing must have three elements:

• It should account for continuity of purpose over time.
• It should be ‘biographically meaningful’, not focusing solely on the ‘here and now’ but incorporating past beliefs and values.
• It should discriminate self from others, that is, it must account for individual variation.

Brändstätter and colleagues argue that it is the ability to balance three sets of processes and perceptions which explains how individuals maintain their psychological well-being and sense of meaning and identity in older age. First, there is assimilation, which comprises the efforts people make to maintain their original goals and aspirations. Assimilative activities are most useful when problems are reversible or can be easily compensated for. However, there comes a time when striving to maintain original goals or standards of performance is no longer productive and accommodation is the most effective strategy. Accommodation involves either downgrading or rescaling performance so that it is consistent with available resources, or maintaining levels of performance but in a different area of activity. In order to illustrate these strategies Lundh and Nolan (1996) use the example of a sportsman who plays top flight rugby. As he ages he might strive to maintain this standard by training for increasingly longer periods but running greater risk of injury. While this can be sustained up to a point by what Brändstätter et al. (1993) term ‘tenacious goal pursuit’, this will eventually lead to disappointment. Alternatively, if rugby remains the desired activity then goals could be reappraised so that active involvement is maintained for example, by playing at a lower standard or by a sideways move into refereeing. On the other hand if competing at the
top level is the main objective, with the sport itself being less important, then another avenue, for example golf, could be pursued. This has a handicapping system which allows people to compete on more equal terms for considerably longer. Although rather simplistic, this example is nevertheless useful as it illustrates that achieving a balance between accommodation and assimilation occurs throughout life and is not just a function of advanced old age. ‘Flexible goal adjustment’ is therefore a key process (Brändstädter et al. 1993).

The theory also suggests that certain ‘identity components’ are so central to an individual’s vision of themselves, that they cannot easily be relinquished. In these situations a third strategy may be evoked, termed ‘Immunization’. This involves individuals selectively interpreting stimuli or events that threaten core identity components, either by playing down their significance or cognitively enhancing their own level of performance. The essence of this theory is that if goals and aspirations are consistent with realistic options then successful ageing is far more likely. Consequently Brändstädter and colleagues argue that accommodation should not be seen as resignation but rather positive adaptation.

While not explicitly following this theoretical approach, other empirical work of a more sociological orientation lends support to this central tenet. Wenger (1997), for instance, suggests that older people who are able to narrow their horizons and accept positively the opportunities available to them report a better quality of life. Similarly, Johnson and Barer (1997) in their extensive longitudinal study exploring how individuals over the age of 85 adjust, found that despite increasing levels of disability, subjective well-being often improved. They argue that social, physical and environmental factors were not sufficient to account for these counter-intuitive results and that an adequate explanation had to incorporate an existential element. In other words it must account for how people find positive meaning in their experiences. On the basis of their results Johnson and Barer (1997) suggest that the key is to ‘reconstitute a self-concept that is consistent with the realities of later life’. This may mean accepting an element of dependency, actively detaching oneself from certain aspects of life and readjusting definitions and meanings. For instance, while most people in this study considered that they still had a friend, this was often a person who some years ago would probably have been seen as an acquaintance. The similarity between this and Brändstädter’s accommodative activities are readily apparent. From such a perspective successful ageing is primarily a process of cognitive readjustment and is best understood on an individual basis, in the context of living a particular life. Therefore Johnson and Barer (1997) contend that relatively ‘small interventions’ can help to improve perceived quality of life, providing they take account of individual aspirations.

The importance of individual perception is mirrored in Baltes and Carstensen’s (1996) explanation of successful ageing. Rather than a normative approach these authors promote an explanation based on
understanding personal goals. Underpinned by the belief that a useful framework must account for the variations in losses and gains that older people experience, they propose a ‘metamodel’ comprising three processes:

Selection: this concept lies at the core of the theory and is about making choices and readjusting ‘individual goals’

Compensation: the use of alternative means to achieve a goal

Optimization: enriching and augmenting reserves and resources in order to support selection and compensation.

Baltes and Carstensen (1996) cite extensive empirical evidence from a number of studies, both their own and those of other researchers, in support of the above processes. Notwithstanding variation in terminology and a subtle difference in emphasis, this approach is basically consistent with the work of Brändstätter and colleagues.

Steverink et al. (1998) contend that successful ageing is a growing theme in the gerontological literature and a major challenge for social policy. While they acknowledge the contribution of the work cited above, they argue that existing theories do not go far enough and that an adequate explanation of successful ageing has to meet three criteria:

• It must focus on individual behaviour and account for changes in physical, social, cultural and psychological circumstances.
• It needs to identify specific goals linked to general behaviours. In other words there has to be greater clarity as to what is being aimed for.
• Criteria for success need to be specified, in order to know when a goal has been achieved.

They propose what they term a ‘Social Production Function Theory’ of successful ageing. The central tenet is that individuals are basically resourceful and seek to maximize their well-being within the constraints that they face. To do so involves ‘framing’ their situation and selecting and substituting goals and activity in the domains of physical and social well-being. Steverink et al. (1998) contend that there is a need to maintain both physical and social well-being in order to age successfully, with five instrumental goals, two physical and three social, providing routes to success. These are:

• Physical well-being
  - Comfort: satisfying basic needs and an absence of fear, fatigue and pain
  - Stimulation: relief of boredom, exposure to novelty, challenge and interesting events.

• Social well-being
  - Behavioural confirmation: performing, or being seen to have performed, adequately in a certain context
The relative contribution of the above instrumental goals in achieving overall well-being varies over time and may be culturally determined or influenced by factors such as gender. For instance, status in adult life is often linked to occupation, particularly for men, and may therefore be more difficult to sustain in older age unless an equally valued activity can be substituted. If this is not possible then achieving status may be relegated in importance and social well-being pursued via either behavioural confirmation or affection. The substitution of instrumental goals is possible within but not between domains. In other words, as a minimal requirement for successful ageing at least one of the instrumental goals in the domains of physical and social well-being must be met. Steverink et al. (1998) suggest that these are usually comfort and affection. When substitution becomes difficult or impossible individuals will redefine themselves and their aspirations in order to pursue goals that can reasonably be obtained.

Steverink et al. (1998) present a number of hypotheses based on their substitution principle for which they provide empirical support from a range of studies. They recognize that important aspects of their theory have yet to be empirically tested, particularly the role of psychological (cognitive) adaptation mechanisms. These aspects do have support from other models such as that of Brändstädter et al. (1993), and so some confidence can be placed in the important role of subjective processes in successful ageing.

The above theories emanate from psychology but there is also work of a more sociological nature that confirms and elaborates upon many of the above concepts. For example Ruth and Öberg (1996) stress, as did Coleman (1997), the importance of a biographical approach to successful ageing, arguing that quality of life cannot be understood simply in the light of current circumstances but must recognize the influence of earlier life, so that the 'life lived gives meaning to old age'.

Kivnick and Murray (1997) propose the concept of 'vital involvement' as a key element of successful ageing, highlighting the importance of focusing on both the problems and assets of old people in order to construct an 'ability balance' based on individuals' values, interests, commitments and strengths rather than simply their deficits. Accordingly assessments and information based on this more holistic approach will be more likely to reinforce the values and beliefs that sustain each individual's personal identity.

The importance of maintaining some form of meaningful involvement is also highlighted by Lawton et al. (1995), who based on empirical work with frail older people living at home suggest that activity alone is not enough, and that older people also need opportunities to engage in
cognitively challenging activities which allow them to demonstrate competence and mastery.

Similarly, writers from a therapy background are increasingly emphasizing the importance of activity being both purposeful and having meaning (Mayers 1995; Trombly 1995). In other words therapeutic activity has a goal or an end point (purpose) but, more importantly, the goal should be valued by the individual concerned. Meaning is therefore essential.

The role of biography, continuity and meaning was highlighted in a study by Nilsson et al. (1998). Based on in-depth interviews with over 60 older people, these authors contend that quality of life has little intuitive meaning for older people, since it is a concept imposed on them by researchers and policy makers. On the other hand what makes for a ‘good life’ in older age is readily understood and older people are able to identify the essential elements. Based on their data Nilsson et al. (1998) created a typology of six ‘types’ of life in older age, ranging from the successful life to the miserable life. Individuals who see themselves as having a ‘successful life’ do not feel old, even in the presence of disability; they perceive themselves as independent even though they may rely on others; they do not dwell on the past but live life for the present and the future, however short that future may be and they usually have strong personal or religious beliefs. In marked contrast those people who see themselves as having a miserable life speak of being old rather than living; do not feel satisfied with their efforts; have poor relationships with others; and rarely engage in meaningful activity. Nilsson et al. (1998) argue that what creates a perception of a ‘good life’ in older age is not related primarily to objective circumstances but to

- personal relationships – a feeling of embeddedness, usually, but not exclusively, within a family context
- activity – engagement in meaningful activity and a feeling of being needed
- links between past and present lives, where the past is viewed positively, as is the future, no matter how short
- a philosophy of life based on religious or other strong personal beliefs.

Not only is there considerable consistency in all the above accounts, but also similar explanations can be found in related fields, such as chronic illness and learning disability. For instance, Charmaz (1983) suggested that a ‘loss of self’ was the fundamental form of suffering in chronic illness, and that this was created and sustained by the overriding focus on physical functioning:

In a society which emphasises doing, not being, those who cannot perform conventional tasks and social obligations lose the very means needed to sustain a meaningful life.

(Charmaz 1983: 191)
More recently Barnard (1995) has argued that autonomy represents one of the most destructive aims for people with chronic illness, and that interventions must instead focus on understanding individual values and aspirations if they are to assist people to relate to life in a way that is responsive to their efforts. He suggests that professionals who thrive on dramatic results and pursue autonomy not only will be disappointed but also do people with chronic illness a disservice.

Within the field of learning difficulties, Renwick and Brown (1996) define quality of life as ‘the degree to which an individual enjoys the important possibilities in his/her life’. This reflects their humanistic-existential orientation and their belief that any framework considering quality of life must recognize that while people locate themselves with reference to a place and social group, they also pursue their own goals and make personal choices and decisions.

There are eight basic premises underpinning their model:

- Equal respect for individuals, regardless of their degree of disability.
- Any meaningful view of quality of life must reflect an holistic orientation.
- Quality of life is multidimensional.
- Quality of life is dynamic and interactive, with the relative importance and emphasis given to various components changing over the life course.
- Quality of life arises out of an individual’s ongoing interaction with his/her environment.
- Quality of life varies depending on personal value systems, beliefs and interests.
- Quality of life requires a broad conceptualization of health.
- Ultimately the personal perspective of each individual is the most important determining factor.

Having identified these basic premises, Renwick and Brown (1996) suggest that quality of life comprises three major dimensions which they term being, belonging and becoming. Being is concerned with an individual’s physical, psychological and spiritual identity. Belonging addresses the ‘fit’ between an individual and his/her interpersonal relationships and their physical, social and communal environments. Becoming relates to personal aspirations in terms of purposeful activity, instrumental activity, leisure pursuits and personal growth.

Given the disparate areas in which these varying theories were developed, the degree of congruence between them suggests that there is an emerging consensus about the important parameters of quality of life which recognize that it

- is a multidimensional construct
- comprises objective and subjective elements, each being ‘weighted’ or given a relative importance dependent upon personal value systems and cultural mores
• is a dynamic and changing entity, varying according to the stage of the life course
• reflects a set of shared concerns but is ultimately a subjective and individual experience.

In the present context the important question becomes ‘What are the implications of this consensus for the design, delivery and evaluation of services for frail older people across care environments?’ We now move on to consider these.

Promoting quality services for older people

The current emphasis on developing services that reflect the aspirations of users and carers rather than the perceptions of care providers (Department of Health 1997a, 1998b) requires, as the quotation at the beginning of this chapter noted, a change in thinking. Certainly one of the primary goals should be to improve or maintain quality of life and as the above review indicates this means paying more attention to individual values and perceptions. Current conceptualizations of quality life and the measures employed to gauge it appear largely inadequate for the task.

As Kane (1999) argues, we need a more ambitious goal, than simply keeping someone in their own home, if interventions are to promote a meaningful life in older age. Similarly in the UK Redfern (1999) has called for a reconsideration of what constitutes therapeutic activity with frail older people, moving beyond statistical to analytic generalizability.

We believe that there is now sufficient consensus in our understanding of what comprises a ‘good life’ in older age from a subjective standpoint to provide a degree of analytic generalizability. What is now required is a synthesis of existing theory so as to enhance its practical application.

However, in addition to focusing on what ‘counts’ for older people and their carers, we believe that quality of care is unlikely to be achieved and sustained unless staff enjoy and value their work. Ageist attitudes and the devaluing of work with older people are still all too apparent in both the health and social services (Health Advisory Service 2000 1998; Social Services Inspectorate 1997). Therefore to be useful a framework must also incorporate staff perceptions and suggest ways in which work with older people can be accorded greater status and value. We offer such a framework below by elaborating on the suggestions of Nolan (1997).

Nolan (1997) was concerned with the lack of a therapeutic rationale for work in long-term care settings with older people and identified six ‘senses’ which he believed might both provide direction for staff and improve the care older people received. The term ‘sense’ was selected deliberately to reflect the subjective and perceptual nature of the important determinants of care for both older people and staff. Although in need of further refinement and empirical testing, some of which will be alluded
to later (see Chapter 3), we believe that the senses have application beyond long-term care settings, offering a degree of analytic generalizability which can help to inform service development across a range of care environments. A summary of the senses is presented in Table 1.1.

In presenting this framework we would like to make two important caveats. First, its focus on the subjective elements of ageing is in no way intended to deny the importance of structural factors. Rather, as with

Table 1.1 The six senses

<table>
<thead>
<tr>
<th>Sense of Security</th>
<th>For older people</th>
<th>Attention to essential physiological and psychological needs, to feel safe and free from threat, harm, pain and discomfort.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>For staff</td>
<td>To feel free from physical threat, rebuke or censure; to have secure conditions of employment; to have the emotional demand of work recognized and to work within a supportive culture.</td>
</tr>
<tr>
<td>Sense of Continuity</td>
<td>For older people</td>
<td>Recognition and value of personal biography; skilful use of knowledge of the past to help contextualize present and future.</td>
</tr>
<tr>
<td></td>
<td>For staff</td>
<td>Positive experience of work with older people from an early stage of career, exposure to role models and good environments of care.</td>
</tr>
<tr>
<td>Sense of Belonging</td>
<td>For older people</td>
<td>Opportunities to form meaningful relationships, to feel part of a community or group as desired.</td>
</tr>
<tr>
<td></td>
<td>For staff</td>
<td>To feel part of a team with a recognized contribution; to belong to a peer group, a community of gerontological practitioners.</td>
</tr>
<tr>
<td>Sense of Purpose</td>
<td>For older people</td>
<td>Opportunities to engage in purposeful activity, the constructive passage of time; to be able to achieve goals and challenging pursuits.</td>
</tr>
<tr>
<td></td>
<td>For staff</td>
<td>To have a sense of therapeutic direction, a clear set of goals to aspire to.</td>
</tr>
<tr>
<td>Sense of Fulfilment</td>
<td>For older people</td>
<td>Opportunities to meet meaningful and valued goals, to feel satisfied with one's efforts.</td>
</tr>
<tr>
<td></td>
<td>For staff</td>
<td>To be able to provide good care, to feel satisfied with one's efforts.</td>
</tr>
<tr>
<td>Sense of Significance</td>
<td>For older people</td>
<td>To feel recognized and valued as a person of worth, that one's actions and existence is of importance, that you 'matter'.</td>
</tr>
<tr>
<td></td>
<td>For staff</td>
<td>To feel that gerontological practice is valued and important, that your work and efforts 'matter'.</td>
</tr>
</tbody>
</table>

Source: Based on Nolan 1997
Minkler (1996), we fully acknowledge their significance but feel there is a need to shed further light on the existential aspects of ageing. Only in this way can we more fully appreciate the importance of subjective components to an understanding of quality of life in older age (O’Boyle 1997) and begin to identify the ‘enrichments’ that services might reasonably provide (Lawton et al. 1995). Second, we do not see the framework as being complete or necessarily inclusive of all potential subjective components. We do believe that it is consistent with the theories previously reviewed and provides a basis for exploring the ways in which services might more fully reflect the experiences and aspirations of older people and their carers. For this to occur, practitioners will need to shed some of their existing professionally derived notions of quality of life and come to ‘know’ older people and their carers. This raises fundamental questions about what ‘counts’ as legitimate knowledge and calls for a redefinition of the relationships between older people, their carers and professionals. This forms the subject of Chapter 2.