QUALITY OF LIFE FOR THE ELDERLY LONG-STAY PATIENT

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Michael J. Denham (ed.), Care of the Long-Stay Elderly Patient, Croom Helm, Beckenham, 1983, 236 pp., £14.95, hardback, £8.95 paperback; ISBN 0 7099 0809 1 hardback, 0 7099 0802 2 paperback.

Long-term care of the elderly patient demands a combination of medical and social provision. To some extent this is true of all care settings, but the balance of the components varies substantially. Long-term care does not have the rehabilitate-and-discharge philosophy of an acute medical setting. The population served is more frail, with more numerous medical and social problems, and because the likely time in hospital is extended, factors affecting maintenance of skills and relationships assume increased importance. Medical and paramedical staff, however, have generally been trained within short-stay settings. Although they recognise the importance of social functioning, both of itself and because of its influence on physical and mental health, it is by no means clear that they have the most appropriate knowledge base. Good physical care does not necessarily mean good social care. Quality of care cannot be equated with quality of life.

All this has been known for some time. What is new is that the most influential figures in long-term hospital care of the elderly, geriatricians, have become aware of the need to re-evaluate the place of long-term care within the geriatric service. This is clearly seen in the publication of the present book which has been edited by Michael Denham. In one of the chapters Peter Millard (Professor of Geriatric Medicine at St George's Hospital Medical School, London) concludes that 'services in England have concentrated too much on rehabilitation and discharge and have therefore ignored the problem of the basic needs of long-term patients' (p. 215). He calls for a rethinking of attitudes to long-stay patients so that people requiring basic nursing care within the state system may nevertheless maintain their personal identity and develop their own interest.

Since redistribution of resources will be required it is important that providers of care are well informed about the critical issues so that mistakes, costly in human and economic terms, may be avoided.

The problems are ethical, political, procedural and practical. Their

solution demands both goodwill and knowledge. Although there is manifestly much goodwill and some knowledge around, reading *Care* of the Long-Stay Elderly Patient one becomes painfully aware that there will have to be greater fusion of these two commodities before life in long-term care improves significantly. Tim Dartington in his chapter 'At Home in Hospital' comes closest to the central issues when he claims there is a lack of clarity in the aims of long-term care. What is the good life for a person in long-term care? Who decides on the goals of care? How should treatment regimes be evaluated so we can see which features of an institution are associated with desired outcomes? These issues – goals, controls, planned environments and evaluation – are central to the strategy of long-term care policy.

Michael Denham's book is a collection of thirteen contributions of varying breadth and style rather than a systematic analysis. If there is a unifying thread it is 'quality of life'. Three of the chapters have this term in the title, and the weight placed on the concept ranges from Denham's modest statement in the first chapter 'Much can, and has been done, to improve the quality of life in continuing-care wards...' (p. 19) to the assertion by four American contributors in the last chapter that 'Quality of life issues are paramount'.

The book opens with a discussion of criteria of quality of life and previous attempts to measure it (Denham) and closes with two very interesting chapters on long-term care in the United States (Hawley *et al.*) and in France and Denmark (Millard). These chapters contrast refreshingly with those supplied by a number of therapists, who write almost exclusively of local experiences without integrating their practice with the wider concepts of the nursing, psychological or educational literature.

What criteria are to be used to judge quality of life: subjective evaluations such as life satisfaction and self-esteem or 'objective' dimensions such as health and economic status? (George and Bearon)¹. After a survey of potential measures (indices of physical and mental health and functioning, health perceptions, life satisfaction and morale – mostly measures developed in a different context) Denham acknowledges that each patient's concept of quality of life will be influenced by culture, experience and training and is likely to differ from that of the investigator. Two things seem to follow from this. First, the care provider has to ask what *use* quality of life data will be in running the institution, and attaining its goals. Secondly, and more generally, the provider has to consider how a coherent philosophy of care can incorporate the issue of individuality, and provide continuity with the patient's previous life style.

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Kane and Kane² elaborate on the first point. The mere existence of the large number of measuring tools listed by Denham does not address the practical question of what use they might be. A measure would certainly be useful if it could be shown to assist in long-term care decision making (e.g. if knowledge of functional ability, say, helped in making appropriate decisions about suitability for treatment or placement). Another criterion for utility would be to regard quality of life measures as an outcome of care, as Davies and Knapp³ suggest. Measures of life satisfaction and morale could then take their place alongside traditional outcome variables such as morbidity and mortality statistics when evaluating a service. (It would still, of course, be a mistake to attribute low or high morale entirely to the characteristics of the treatment regime, since low self-esteem or unhappiness might have been life-long or triggered by losses sustained before entering care.) Either case for utility rests on empirical evidence of the validity of the measures, predictive or constructive, preferably derived from longitudinal studies. This is largely lacking, and nothing in Care of the Long-Stay Elderly Patient contributes substantially to this validity issue.

The realisation that quality of life means different things to different people forces us to examine the goals of institutional life to see which are global and which particular. Goals may of course change as the patient's state alters. We can assume, however, that quality of life for the long-stay patient depends in part on quality of medical and nursing care. A global goal must therefore be to allow access to the standards of health care available to others in the community. This implies constructing an environment which encourages maintenance of social and instrumental skills rather than deterioration. Design of the physical and social environment plays the major part in attaining such goals, e.g. providing the least restrictive environment; promoting personal space and control; providing a context which is sufficiently demanding to counter the 'mindless' information-processing strategies to which Langer⁴ suggests the old in institutions are prone.

There is a fair-sized relevant literature on how environments may be designed for the elderly. This is not really covered in Cullen's chapter on 'Nursing Care' or Clarke-Williams' on 'Ward Furniture and Equipment'. Although their suggestions on ward arrangements are sensible, there is no discussion about the magnitude of any expected impact on behaviour and morale. True, one may argue that in a psychological barren environment almost any change will result in increases in patient and staff well-being, but if resources are to be redistributed it is important to ensure they are directed to areas where their effects will be more than trivial. The psychological literature cannot yet quantify minimum standards of psychological and social care below which no institution should fall (akin to nutritional or economic indices) but sufficient grounds already exist for supposing that highquality psychological care demands provision of opportunities for sensory and intellectual stimulation, personal attention and choice with respect to privacy, bodily functions and use of time.

If *individual* interests and preferences play a role in quality of care, environments that are helpful to some patients may be harmful to others. Behavioural ecology assumes that behaviour (and well-being) depends on an interaction of personal and situational characteristics. Though Denham's book is atheoretical, a body of theory does exist which develops these notions (see Lawton, Windley and Byerts).5 Lawton's hypothesis is that the optimum range of stimulation for an individual depends on his or her behavioural competence; the less competent an individual the less environmental 'press' can be tolerated within a given range of adaptation. Furthermore, the impact of environmental change will be more for the less competent (and hence more vulnerable) resident. Kahana⁶ has elaborated the concept of goodness of fit (congruence) between dimensions of the institution and characteristics of the person, and tested hypotheses about the effects of mismatch on morale. The technique involves assessment of both the care setting and the individual. In general, person-environment congruence is related to morale. For privacy, however, an 'oversupply' relative to personal preference is associated with greater will-being, whereas for activity and stimulation, congruence is the optimal match. These ideas have not been tested in a British context but they raise issues of selection and the need to make long-stay environments responsive to patients' needs. Continuity with the past was one of the dimensions Kahana investigated. The rather pathetic photographs in Denham's book of elderly people playing tambourines, 'ward hockey' and hoops (whilst in the background an elderly woman stereotypically sucks her thumb) underline the need to take past activities and age appropriateness into account in planning ward activities. As George and Bearon¹ point out, receiving services earmarked for the 'helpless' or 'needy' will reduce self-esteem in some individuals and thereby reduce their quality of life.

A responsive environment requires individual goal setting and evaluation and it is unfortunate that Denham's book does not address this issue centrally. Goal planning is integral both to behaviour modification (dismissed in a paragraph) and to the problem-oriented 'Nursing process'. It involves specifying defined objectives together with a statement of preconditions (*who* must do *what*) and consequences, so it appears a particularly germane procedure for the long-term care setting. It is possible to set and review both short- and medium-term goals. The chapter by Hawley *et al.* from Monroe Community Hospital, Rochester mentions the use of written care plans. There, the care plan is written within two weeks of admission, reviewed monthly, updated quarterly and rewritten yearly (p. 224). Although it is not stated how such care plans are evaluated the system seems to have much to commend it.

Staffing as an issue in long-term care is one that Denham as editor seems to evade. There is much talk of 'immense job satisfaction' (a geriatrician) and of 'appreciating the satisfaction of working in departments of geriatric medicine where the emphasis is not on custodial care...' (a nurse). Great stress is laid on the value of case conferences and on the multi-disciplinary team, without any analysis of what problems are to be referred to the team, how information is to be exchanged, how decision-making is to be expedited and whether members of the team are satisfied with decision-making procedures. Cullen notes the low levels of trained nursing staff in geriatric medicine in general and long-term care in particular. Many nursing auxiliaries receive no training whatsoever and staff may 'arrive by direction rather than by choice' (p. 65). There is confusion, too, about the role of volunteers - whether they should be trained or whether training reduces their value. Staff have such a momentous influence on patient care that the subject surely deserves a chapter of its own.

Institutions are powerful determiners of the behaviour of staff and management as well as residents. The institution serves many functions, of which patient care is just one. Long-term care serves a social function, relieving strain on families and on other parts of the welfare system. Families and management may be more concerned with quality of care and avoidance of scandal than with quality of life (Davies and Knapp).³ Additionally institutions provide the rationale and context for work of professional and care staff. Chapters by Alvin, Jones and Poulden show that careers in music, art and education are joining the traditional medical, nursing and therapeutic careers. The goal of improving quality of life for patients has to be viewed within this broader context. Changing environments means changing what staff do, and there is likely to be resistance to procedures which, even if they improve patient care, reduce staff satisfaction or privilege. The issues are those of control and counter control.

Dartington's chapter raises the question'...is it a reasonable demand to ask those working in a hospital setting to provide a home-like environment?'. A person at home has, he argues, a personal authority to match the authority of others, but this is undermined when the patient enters a long-stay setting. Control over personal goods, decisions and connections with the outside world have to be rendered up. Even in 'enlightened' institutions where there are activities, privacy and choice, there is a sense in which a patient's 'control' is illusory because it is a privilege to be withdrawn if circumstances change. The tragedy of long-stay patients lies in their *lack* of influence on the behaviour of those who look after them. Private patients may have more clout, as Millard notes (p. 209). In Denmark, long-stay patients have individually furnished single rooms with lavatory and shower facilities as basics. This seems to sway the balance of 'control' towards the resident, at least to the extent that staff invariably knock before entering the patient's territory!

The fact that institutions serve staff interests as well as residents' means that seemingly undesirable practices may have positive side effects. Batch processing of patients leads to predictability of work flow and enhances a nurse's sense that useful jobs are being done. An unpublished study by Abigail Gilbert⁷ found that nursing auxiliaries in continuing care perceived their day in terms of jobs to be 'got through'. A successful day was one in which the jobs were 'completed' early so that there was time for some relaxation (with other nurses) before the next shift came on duty. This time was seen as a just reward for effort expended. A system of nurse management that emphasises continuity of care throughout the day cuts across this informal self-reward system. As numerous studies have shown, a 'successful' programme which yet reduces staff satisfaction is highly likely to be abandoned. By the same token, programmes such as Reality Orientation, which provide a rationale for staff activity and improve staff morale are likely to be espoused enthuiastically in spite of meagre gains for patients and negligible generalisation (p. 194).

The possibility that for staff and residents a 'successful outcome' differs means that very *specific* goals must be evaluated. Nurse-patient social interaction is habitually low in long-term care and might seem a reasonable target for intervention. However, the assumption that staff interaction is beneficial to patients is not necessarily justified. Baltes and her co-workers ⁸ analysed interaction in terms of sequences of *type* of behaviour. They found that dependent, helpless behaviour on the part of residents was differentially attended to by staff and independent behaviour ignored. On this evidence, increasing staff-patient interaction would tend to increase patient dependency unless the type of interaction could be altered without reducing staff morale.

One interesting possibility raised by Care of the Long-Stay Elderly Patient is that of extending the number of roles 'manned' by the long-stay patient. A mentally intact elderly patient could be student, tutor, counsellor – giving rise to a variety of social roles each with characteristic pattern of interaction. Sidney Jones in his chapter 'Education and Life on the Continuing-Care Ward' discusses patients as students and asserts that the educational experience is beneficial because it is freely chosen by the elderly person, and requires frequent active communication with the teacher and fellow students on matters of shared and sustained interest.

Care of the Long-Stay Elderly Patient is something of a pastiche. There is much that is of interest, and much that is provocative. The tone of the book is of professional optimism – though as the speech therapist Sylvia Meikle sagely remarks in her chapter on 'Communication with Patients in Residence', 'Unfailing optimism can sometimes have the opposite effect and cause greater retreat and depression' (p. 118).

Feelings of depression on reading this volume centre on its relative parochialism concerning European and American work and on the low standards of enquiry that seem to be accepted within the field of long-term care evaluation. Evaluation by anecdote is mistaken for testing of hypotheses, collection of data and scrutiny of evidence. A report that during an educational programme 'the participants' eyes are brighter' (p. 132) is not without interest, but in the absence of before-after comparisons or systematic measurements (both of those taking part and others) it is simply inadequate. (Who records 'brightness', the teacher or an independent assessor? Does 'brightness' occur only in class or does it generalise to other situations? Do health-related measures vary concomitantly?) These and similar methodological issues are not trivial. They are central to the compilation of a valid data base without which there will be no knowledge to accompany goodwill when the resources at last come within the grasp of those providing long-term care.

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NOTES

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