

Long-term Assistance and Care for Dependent Elderly and People with Dementia

by

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During the last century, the increase in life expectancy and longevity resulted in a sizeable growth in the proportion of elderly people in developed countries. This demographic change brought about an increase in the prevalence of neurodegenerative diseases (particularly Alzheimer's disease and related disorders). These chronic, progressive diseases are characterized by mental disorders (cognitive, psychiatric and neurological) causing progressive disabilities in the activities of everyday life (instrumental and daily living activities). The sick person then becomes dependent on the assistance of a third party to ensure his survival (1).

Dependency: a new medical risk

Functional disabilities in the elderly were formerly seen as the inescapable consequence of ageing: a normal risk inherent in life. For about thirty years now, the term "dependency" has been used to define situations with disabilities in people aged over 60 years (that

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of “handicap” being reserved for younger age groups). Considered as the consequence of a chronic pathology (physical, mental or psychological), dependency has acquired the status of a new medical risk which must be recognised by the social welfare system. This recognition has confronted the developed countries with the problem area of long-term aid and care. The continuity and integration of services in this area raises numerous points of concern: 1) better integration of health and social services in community-based care; 2) restructuring and development of institutional services to promote good quality care (temporary and longstay services); 3) number and qualifications of formal caregivers; 4) assistance and support for families and for informal carers (proxy services); 5) cover for and financing of social and health costs (2). The response to these problems varies for each country according to the social welfare system, social and health policies and professional practices.

Dependency and long-term care

The policies of aid and long-term care are based on the concept of dependence (3). This concept is multifactorial and multidimensional and is not defined solely by biomedical factors (4). Illness and disabilities do not necessarily imply dependency. Numerous psychological and environmental factors can play an important role in its development. It is usually identified by 4 criteria: 1) causality (risk occasioned by the disease); 2) purpose (need of the assistance for everyday activities); 3) degree (significant and regular assistance); 4) period (need of assistance for a minimum period). Initially, dependence was defined as physical and/or instrumental (relating to physical and/or sensory deficiencies). At the present time the term psychic dependence emphasizes the influence of mental disorders (cognitive, psychological and behavioural).

The individual assessment of dependency must make it possible to clarify the needs for care and then determine the methods to be implemented to cover them and ensure financing. This assessment takes into account first the physical dimension, and then the psychic. The areas considered and the criteria and methods to be adopted are very variable. Many countries choose to use a standardized instrument (scale, grid, questionnaire) which lead either to an individual care planning or the classification of subjects in various categories (iso-resource groups) according to the degree of dependence/independence. This instrument also helps to determine both the nature and extent of the aid and care to be provided and their costs.

European states with a Beveridge-type welfare system (universal rights, collective social responsibility) have, to varying degrees, incorporated long-term aid and care into their social and health systems (Scandinavian countries, United Kingdom and Ireland). The Bismarck-type countries (obligatory insurance limited to recognised risks) have also adapted their systems, but have also engaged or completed discussions on the creation of a specific insurance system (dependency/autonomy insurance). The Netherlands, Austria, Germany, Luxembourg, France and the Flemish Region (Belgium) have introduced legislation in the area. In the Southern countries, discussions are less advanced, but Spain and Italy have already taken a series of legislative steps.

Belgium and long-term care

In 1982, Belgium began the restructuring and adaptation of its social and health system to ensure continuity of care for dependent and demented people. The measures taken concern cover for and the financing of health and social risks, as well as institutional and community services. Family and local community services were given less attention (5).

Cover for and financing of dependence

Medicalised costs relating to dependence are covered and financed. Nursing home beds (*maison de repos et de soins-MRS/rust en verzorgingstehuis-RVT*) benefiting from specific financing, were created in 1982 for very dependent elderly people (6). These beds are allocated to residential homes. For the other residents, a set daily flat-rate allowance has existed since 1991, according to the degree of dependence. In 1993, this system was extended to persons housed in their own home and cared for by community-based care services.

The degree of dependency is assessed by the formal caregiver using a standardized instrument (Katz scale – INAMI/RIZIV modified version) (7). The subjects are classified in 5 iso-resource groups (O, A, B, C, Cd). The flat-rate allowance for each group is paid directly to the institutional managers. The amounts received are used to pay the formal skilled caregivers (number fixed by legal standards). This system is at present the subject of much discussion. The assessment methods and the suitability of the Katz instrument are questioned and other approaches are being considered.

Policy choices have concentrated on the financing of formal skilled services (implicit dependence insurance). They have principally con-

tributed to the development of the formal care sector, while that of informal care has been much less involved. The question of explicit additional insurance (paid directly to the patient) is being debated at the federal-state level.

Restructuring and development of the institutional care system

The institutional care system has undergone radical change in the areas of residential care and intermediary structures. Hospital departments for the elderly have been set up (geriatric and psychogeriatric departments). Qualitatively and quantitatively, service availability is above the European average. However, it is less so with regard to the intermediary structures (service flats, sheltered accommodations, day-care centres, multifunctional houses).

Coordination and adjustment of the community-based care system

The community-based care system continues to be characterized by the distinction between social and health services. The diversity of organising powers and methods of financing does not facilitate coordination and structural development. It is moderately well developed with a great variability in the services offered. The latter are centred above all on caring for the physically dependent. With certain exceptions, no particular steps have been taken to target demented people. Globally, the community-based care system has not yet completed its functional adaptation, despite many changes.

Aids and support for informal carers (family, neighbourhood, local community service)

With the exception of some financial measures (e.g. social tax deductions), Belgium has not yet defined a specific policy concerning the informal cares or support for the carers (family or others) of dependent or demented relatives. This delay is due to a lack of social pressure, or a cultural tradition which considers family solidarity as "natural", or perhaps the lesser prestige enjoyed by volunteers.

Long-term care to people with dementia

No country has developed a policy specifically targeting people with dementia. Measures taken belong to general policies of assistance and care for dependent people. They try to gain a better integration of community-based care services (social et health) and to improve quantitatively and qualitatively the residential institutional care system. Efforts

are also directed at maintaining the well-being and quality of life of the dementia sufferers as well as at supporting families and informal carers.

Given the questions and problems raised by care to dementia sufferers, the INAMI/RIZIV (National Sickness and Disablement Insurance Institute) of Belgium published a market supply curve in 1998 entitled "Etude Démence" (Dementia Study) (8). Its objectives were to draw up an inventory of information related to dementia (epidemiology, diagnosis, resources of care, assessment of care needs), to define a quality service which provided care and support for dementia sufferers and their relatives, and to elaborate suitable methods of intervention by an obligatory health-care and insurance system.

In this perspective, the study specifically had to deal with: the selection of a reliable diagnostic procedure of dementia and its staging; the choice of a procedure and instruments for the assessment of care needs throughout the dementia evolution; the definition of the role of the different players (community-based care, hospital, residential facilities, specialized units) and desirable features of built environment (architecture, ergonomics, material device); an operational definition of the quality of life in dementia; proposed procedures and techniques of care, support and environmental adaptation; assessment of the work load and resources of care by sector and discipline; the definition of the financing means. In addition, the procedures, instruments and techniques deemed appropriate had to be experimented on a representative sample.

QUALIDEM study

The study was entrusted to an association, labelled Qualidem, which involves researchers from Catholic University of Leuven (KULeuven) and University of Liege (ULg). The research team is directed by F. Buntinx, J. Delepeleire, O. Fontaine and M. Ylief.

A first report (October 2000) summarized the epidemiological data, the care resources by sector and discipline, the procedures and instruments for diagnosis and assessment of care needs published in the scientific literature. The conceptual and methodological problems raised by the definition and assessment of the quality of life in dementia were discussed. The initial conclusions about care needs and quality support were drawn, together with those concerning the adaptation of the environment. Finally, the procedures and instruments to be used for testing a representative sample were selected. The selection was based on their psychometric properties but also on their reliability, feasibility,

cost and control possibilities. This report is available on the Qualidem website (www.ulg.ac.be/psysante/qualidem).

In December 2002, the final report was principally concerned with the findings of the experimental study. This study was conducted simultaneously in two administrative districts (Lier in Flemish Region and Verviers in Walloon Region). A sample of 4450 subjects 65 years old and over, who had been assessed as frail, was set up (Phase I). An in-depth cognitive assessment made it possible to isolate (Phase IV) 402 subjects with dementia (target group), 57 subjects with cognitive disorders (depression, delirium, MCI) and 32 normal subjects (control group). The analysis of the data gathered in these 3 groups confirmed the sensitivity, reliability and feasibility of the instruments selected for the clinical diagnosis of dementia and its staging, psychological and behavioural disorders and the quality of life. The comparative study of the various instruments for assessing care needs made it possible to show their respective contributions, convergences and limits. These instruments are Katz-INAMI/RIZIV, AGGIR grid (9), PATHOS questionnaire (10) and the Resident Assessment Instrument-RAI (11). The work load of professional caregivers and the burden of family caregivers are detailed. The costs of both residential institutional and community-based cares are estimated. Detailed proposals for financing and monitoring are made. Finally, consensual recommendations for qualitative and humanitarian care (psychosocial and pharmacological) are given and discussed. This report is also available on Qualidem web site.

The second phase of the Qualidem study is now in progress (2003-2005). It is principally concerned with the prospective analysis of the development of care needs in the different groups of the first phase.

The editorial board of the revue agreed to publish several articles on the data arising out of the Qualidem research. Paquay and colleagues describe the study protocol and demonstrate the methodology of the experimental study on a representative sample of the two administrative regions (Lier and Verviers). Pacolet and colleagues show the results of the comparative cost analysis of community-based and institutional care. The costs found are less than those reported by other studies. De Lepeleire and colleagues highlight the advantage of the FRAIL scale (12) for the general practitioner. This standardized instrument is very useful for screening frail subjects and has good psychometric properties (specificity, sensitivity, validity). Shoenmakers and colleagues analyse the data gathered from the family caregivers of close relatives suffering from dementia. These findings confirm the very heavy workload and the presence of depressive symptoms. However, they are not significantly

different in the control group. De Lepeleire and colleagues also describe the organisation of home care and its evolution in Belgium. Finally, Buntinx and colleagues present and discuss the new proposals for financing care in three stages.

The amount of data gathered, the diversity of the analysis carried out and the wealth of the results achieved by Qualidem study will certainly contribute to the elaboration of a global, coherent and specific policy for quality care and support for dementia sufferers and their relatives.

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