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SYSTEMS OF CARE FOR FRAIL OLDER PERSONS

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As stated by the Director-General of the World Health Organization in her speech to the fifty-first World Health Assembly in Geneva, on May 13, 1998: "We have another transition, the transition from the communicable to the non-communicable diseases." Also as she pointed out, an appropriate degree of attention to acute infectious illness is not at odds with a special emphasis on chronic conditions and the consequences of chronic disease. In her words, "They cannot be seen as competing tasks. They are complementary. We need to fight both. The burden of disease is the burden of unfulfilled human development" (1). Nowhere is this viewpoint more important than in the prevention of frailty and the design of systems of care for the frail elderly so as to maximize function and quality of life. All persons in all countries endorse these goals for themselves, their elders, and even their children. This changing direction at the World Health Organization reflects both the change from acute to chronic illness worldwide and the dramatic demographic shift as almost all countries witness the aging of their populations. As noted by Kinsella and Taeuber of the Bureau of the Census of the US Department of Commerce, "In 1991 the net balance of the world's elderly population grew by more than 800,000 each month. Projections for the year 2010 suggest the net monthly gain will then be in excess of 1.1 million elderly people" (2).

All health care professionals would agree that if care for the individual is to be exemplary, a comprehensive assessment is required. Similarly, if care is to be provided to populations in a cost-effective manner, a standardized assessment of need is necessary so that data can be grouped, risk factors for disease and frailty uncovered, outcomes of interventions measured and quality of care addressed on a continuing basis. These points deserve emphasis because an abundance of resources is not a prerequisite for many effective health care policies.

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What is required is the avoidance of waste. This can only be achieved by determining an individual's needs with precision and utilizing targeted interventions. On a more global basis we must learn from other nations, thereby avoiding costly interventions which have already been shown to be wasteful or not effective just across a border. It must also be appreciated that standards for quality of health care are always in evolution as science introduces new technologies, drugs, and systems of care, which require repeated evaluation. As we enter the twenty-first century, many if not most countries must address this issue: how to provide care on a continuing basis effectively and efficiently to a population which is aging and burdened with an increasing prevalence of chronic disease resulting in increased frailty and decreased function (3).

During the period 1989–1992 under contract with the federal government in the United States a group of investigators designed a standardized assessment-of-elders instrument for use in skilled nursing facilities (4). The Resident Assessment Instrument (RAI), as it is known, was field-tested, tested for validity and reliability and ultimately mandated for use in all 1.7 million nursing-home beds in the country. Computerization of the data is now mandated throughout the United States, and both the Province of Ontario, Canada and Iceland have recently formally adopted it as well. Seven million completed assessments on over 3.5 million individuals including longitudinal data on large numbers are stored at the University of Michigan, the University of Michigan Assessment Archive Project (UMAAP).

About five years ago an international group of over 30 researchers was formed under the auspices of a not-for-profit corporation, inter-*RAI*, dedicated to research and policy development in elder care. Its fellows, as they are known, and their local collaborators directed their attention most especially to the frail elderly population. They began by translating the Resident Assessment Instrument into eleven languages, thereby allowing for its use in a large number of nations. This permitted each to have a better appreciation of the unique needs of that country in the long-term institutional setting as well as the opportunity to compare its requirements and its systems of care with those of other nations.

At present, researchers from 16 countries including Canada, the Czech Republic, Denmark, Finland, France, Germany, Great Britain, Iceland, Italy, Japan, Norway, the Netherlands, Spain, Sweden, Switzerland, and the United States, participate in this initiative, which is made possible because even definitions and training are comparable across national borders. Standardized assessment virtually identical

in content, even if written in different languages, allows nations to learn from each other. Groups of individuals can be stratified and outcomes of care resulting from both medical interventions and fiscal decisions can be contrasted. Designing or redesigning a national system of health and social services for a frail elderly population requires these four capabilities: 1) a comprehensive evaluative process on an individual level; 2) the identification of the unique needs of each person which preclude that individual from achieving a maximal function and quality of life; 3) a corresponding service directory, be it formal or informal, in the public sector or the private; and 4) a continuing process of evaluation on both an individual and group basis, thereby permitting ever more targeted and effective interventions.

All steps are inter-related with, for example, decisions as to service provisions determined to a degree by the type and prevalence of specific needs and how effectively they may be addressed or prevented by a given intervention. This schema also allows for a process of prioritization by nations which appropriately may choose a relatively inexpensive intervention applicable to the needs of a large number of individuals rather than an expensive intervention directed to the needs of just a few.

The investigators at inter*RAI* have developed or are in the process of designing assessment tools for use in multiple other sites of care, including the home and the community, the hospital, the assisted living setting and the mental health facility. These forms have many items and domains which are identical or nearly so to the original Resident Assessment Instrument. These assessment tools "cross-talk" and will, when completed, make possible a person-specific rather than a site-specific assessment of need and care planning (5). This in turn will optimize the capability of making a directed needs-based series of decisions in the care of a unique person and of grouping data elements to allow for effective targeting of specific interventions to groups and subgroups across settings.

As noted by Hirdes and colleagues, outcome measures have been developed for use with the RAI instruments (6). They include the Cognitive Performance Scale (7), the Resource Utilization Groups (RUG-III) (8), and the Index of Social Engagement (9). Longitudinal studies are underway in multiple countries to assess both the mental health and the quality of life of nursing home residents. This ability to contrast populations which are in fact comparable is especially important as what passes for a nursing home in one country may bear very little resemblance to a long-term care institution in another. As Ribbe *et al.* have noted, at the present time long-term care resource develop-

ment bears little resemblance to the aging status of a nation or to patient need (10). The adoption of a RAI series of instruments by many if not most nations with the associated outcome measures will allow for the rational design of systems of care for the frail elderly and analysis to support the best possible outcomes for the least expenditure. For example, the Resource Utilization Groups (RUG-III) as developed by Fries and others allows for the explanation of 55% of the variance in resource use in long term care facilities. Carpenter *et al.* have illustrated that the RUG resource use casemix system explains how nursing time is distributed among residents of long-term fare facilities in the same way although characteristics of the services and the amount and training of staff vary enormously (11). The clinical characteristics of those served determines resource utilization regardless of which country these persons reside in.

In addition, care plans that warrant review and revision may be identified by any number of mechanisms. Simple comparisons of populations of countries may highlight important issues which require more detailed consideration. For example, Ljunggren *et al.* have reported marked variation in the use of patient restraints in nursing homes. Less than 9% of the persons in long term care settings in Denmark, Iceland and Japan are restrained in contrast to 15 to 17% of those in France, Italy, Sweden and the USA, and almost 40% of individuals in Spain (12). These differences persist even when populations are adjusted for physical and cognitive abilities.

One of the most important potential uses of RAI data is likely the research initiative developed by Mor et al at Brown University, Providence, Rhode Island, the USA. They have meshed drug utilization data with that provided by the Resident Assessment Instrument describing patient characteristics. This enterprise, known as the Systematic Assessment of Geriatric Drug Use via Epidemiology (SAGE) allows for the matching of patient need with drug intervention (13). This group pointed out that a very significant number of persons in nursing homes in the United States with a diagnosis of cancer who complain of pain daily fail to receive adequate analgesia or even any analgesic agent at all. This study, to be found in the June 17, 1998 issue of the *Journal of American Medical Association*, was reported on the front page of the *New York Times* and *USA Today* and covered by CNN and a number of other worldwide television networks (14). It was subsequently commented on in an editorial in the *Wall Street Journal* and perhaps most importantly, a Doonsbury cartoon strip which is widely read in the United States and throughout much of the developed world. A detailed analysis of pain management in multiple nations is now in

process. Thus, RAI instruments designed by an international group of investigators can be utilized to uncover issues of considerable importance within a single nation, and others which are common to many nations. It may even draw the public's attention to these issues and hopefully effect change.

As all of us age, we stare frailty in the face. Nations will be required to address the needs of millions of us everywhere in the world who are approaching this stage of life. They will be required to do so in the most cost-effective manner if they are to do what they must to be great nations who assure all their citizens the opportunity to achieve the highest quality of life over a span now approaching a century in duration. Each nation shares this endeavor with all others by talking the same language and desiring the same ideals even as programs and policies are adapted to the individual cultures that sprinkle the globe. Each nation's goals will be achieved by collaboration on an international level never before imagined possible but now readily available. Such collaboration will allow all nations to share in the successes of their neighbors throughout the world, allowing each to be not only an effective provider of care at home, but a partner in the care of all humanity.

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DISCUSSION

Kohler, Oregon Health Sciences: I was very interested to hear of your instruments, Knight. There are a couple of objectives that could be achieved by this. One is to improve care wherever the people are. I was wondering, will these, or this, (I'm not quite sure what to call it) be used to compare sites of care? For example, if you can look at the differences between assisted living, a nursing home, and home health care, and are trying to decide which might be preferable, can this instrument be used for that purpose?

Steel: You must have been sitting in on our conversation just a couple of days ago in Toronto. We were discussing exactly this. We already are in the process of doing that. The UMAP (University of Michigan Archive Project) data base has huge amounts of data, not only in long term care, but also, for example, in home care. The RAI instrument, although not mandated for home care by the federal government, is now mandated by a number of states in the United States, so our home care instrument which cross talks and cross walks with the long-term care instrument in nursing homes does allow for exactly this comparison. We are beginning to put that data together. Also in keeping with John Eisenberg's comment earlier about the differences in the use of services around the country, it is striking, for example, that for some conditions there are six times the number of home visits in one location as there are in another. The trick is you also have to adjust that population to be sure, in fact, that you are talking about the same group. This absolutely can be done, and is being done, and a whole series of papers are coming out on this.

Calkins, Buffalo: Knight, it is exciting to have followed your career and the development of this program over twenty years. I know it has been a long commitment on your part and to see it emerging in this fashion is really exciting.

Steel: We are also interested in working with groups who might introduce a clinical intervention in one or another location and compare outcomes with and without the

intervention. Inter RAI, a not-for-profit corporation, was established a number of years ago with the purpose of supporting all academic centers and researchers to participate in research in this area. If you have a for-profit company that would like to give us money or perhaps use our seniors, we'd be happy to talk to you about that too, but that is not the purpose of Inter RAI!

Cerda, Gainesville: In the state of Florida where we have a considerable number of people who I consider to be sophisticated, the press and many organizations perceive that physicians really don't care about what is going on. Because of that, there is a great push for nurse practitioners and physician assistants to do a lot of what I think is physician care. I wonder if you have any comments on this?

Steel: That is a whole separate issue. I think the first issue is to decide what the need is and then one can decide what intervention, including what service and what professional, is best qualified to provide that intervention in the cheapest possible way. I think we don't really need to make the assumption that, for example, it really even requires an ophthalmologist to take out a cataract. For example, there may be opportunities down the road to train a technician to do nothing but take out cataracts. My personal bet would be that you could actually train some awfully good technicians to do that. I am glad there is nobody here from the American Academy of Ophthalmologists!

Barondess, New York: Knight, I was struck by the country-to-country variation in the application of restraints in patients in chronic care facilities. It made me wonder and I want to ask you whether you think that reflects variations from country to country in the availability of certain types of personnel, or other supporting kinds of help, or whether you think it reflects variations in attitudes about the sick or the elderly or the validity of the chronically ill role.

Steel: Excellent question. If you will allow the fact that there is no real science to my statement—it is just speculation—I think it is a little of all of that. There is some evidence, for example, that the reason that people in nursing homes lose weight consistently is not that they just lose weight because they are "wasting away" in a nursing home, but because there aren't enough people to feed them. It may be a combination of culture, resources, allocation, legal precedent, and a number of other issues are involved. Clearly, there has been a huge move on in the United States to decrease the use of restraints, and that has been very effective.

Barondess: Are there any data about national attitudes concerning the elderly? Are there any data about how they perceive the elderly?

Steel: There are a lot of discussions about how elderly are perceived. It has been my experience that often there are misconceptions about what other countries think. For example, when I was in Geneva, I was persistently told that Americans don't pay any attention to their elderly and that they really do care much more in Europe. That is clearly not the case.

Billings, Nashville: Knight, is there any data base which includes information regarding the probable great contrast between those elderly people who are healthy, old and not in nursing homes and those who are unhealthy and flawed and who are in nursing homes? This would be the top of the peak and the bottom of the peak. It seems to me there might be some value in making some kind of contrast like this. The in-between is shady, but how have these people reached the bottom and what is the contrast, the difference between the bottom and the top? Is there a data base on that?

Steel: Yes, there is. There are two points I will make to that. I didn't bring a lot of data, but we have data, for example, comparing the populations who use home care and the populations who use nursing-home-care based on the same cross-talking set of assessment instruments. So we can tell you on a population basis what these populations look like and quite clearly there are major reasons for people to end up in nursing homes,

certainly in the United States. Also, there is work that has been just completed by Brant Fries and others looking at our centenarian population, which by definition is relatively healthy since they got that far, and you will be interested to know that the population being studied is about 2,000 centenarians. Regrettably, I don't have the data from that study.