

Health Outcomes among the Frail Elderly in Communities and Institutions: Use of The Minimum Data Set (MDS) to Create Effective Linkages between Research and Policy

John P. Hirdes, *University of Waterloo and Providence Centre* and G. Iain Carpenter, *University of Kent at Canterbury**

RÉSUMÉ

Les chercheurs et les décideurs qui s'intéressent aux besoins des aînés fragiles vivant dans leur foyer ou en établissement ont obtenu des résultats limités en fondant leur politique sur des données empiriques. Cette situation résulte de multiples considérations d'ordre organisationnel et politique (manque de mécanismes de communication efficaces), de problèmes méthodologiques et conceptuels (difficultés quant à la fiabilité et la validité des sources de données actuelles) et de limites de connaissance (manque de données longitudinales du secteur des soins de santé). Le Minimum Data Set (MDS) pourrait se révéler utile pour pallier à ces difficultés. Les instruments qui le composent présentent des usages multiples appropriés aux différents destinataires (fournitures des soins, financement et amélioration de la qualité). Des expériences répétées à l'échelle internationale ont démontré que le MDS est valide et fiable et il est traduit en 11 langues. Comme on commence à l'utiliser au Canada, il soulève d'autres préoccupations qu'il faudra voir à régler (confidentialité, accès aux données).

ABSTRACT

Researchers and policy-makers interested in the needs of the frail elderly in community and institutional settings have had limited success in forming policy based on empirical evidence. The reasons for this have included a variety of organizational and political considerations (e.g., lack of effective communication mechanisms), conceptual and methodological issues (e.g., problems with reliability and validity of existing data sources) and limitations in knowledge (e.g., lack of longitudinal data across health care sectors). The Minimum Data Set (MDS) series of instruments may prove useful in dealing with these difficulties. The MDS instruments have multiple uses for different audiences (e.g., care provision, funding

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John P. Hirdes

Department of Health Studies and Gerontology

University of Waterloo

Waterloo, ON N2L 3G1

and quality improvement). Extensive international testing has shown the MDS to be valid and reliable, and translations are available in 11 different languages. As implementation of the MDS begins in Canada, a number of new concerns will need to be addressed (e.g., confidentiality and access to data).

Introduction

In the context of increasing expenditures and decreasing resources for health care services, the need to evaluate service delivery to all Canadians, including the frail elderly,¹ has become paramount. A central issue in this focus on evaluation is the need to develop effective outcome measures of health and quality of life. Such outcomes may be used in a number of ways, including: (1) improving health and quality of life of the frail elderly by identifying interventions that lead to the greatest change in outcome measures; (2) improving the quality of care and service delivery by using selected patient characteristics as quality indicators; (3) increasing cost-effectiveness of service delivery by identifying programs and services able to attain specific outcomes at the lowest cost; and (4) increasing the cost-benefit ratio of programs and services based on a comparison of the relative gains in outcomes with the relative costs of interventions. These analyses would be of interest to any organization providing services to the frail elderly, but there is also growing interest in the completion of regional or national comparisons to identify the most appropriate models of service delivery.

Despite widespread interest in the use of health outcome measures to improve the situation of the frail elderly and to improve service delivery, progress at the macro level has been tentative, disparate, and convoluted. The major factors hindering the evolution of outcome measurement for the frail elderly can be grouped into: organizational and political considerations; conceptual and methodological issues; and limitations in knowledge. A broader review of each of these main areas follows. Next, a number of alternative approaches will be examined with respect to their ability to provide a viable framework for health outcome measurement in this population, and a new model building on existing approaches will be proposed. Finally, a number of new and unresolved issues are discussed, with respect to implementation of the proposed model in the Canadian context.

Organizational and Political Considerations

The development of appropriate health outcome measures to be used in policy development and service delivery requires a strong partnership between service providers, government and the research community. However, a number of factors have limited the effectiveness of these partnerships.

Although it is clear at first glance that service providers and the research community have valued resources that each may offer and the other needs, there has been a surprising lack of affinity between these groups. Service

agencies typically do not have adequate resources to do reasonable quality research, despite growing pressures to move to models that emphasize evidence-based practice. On the other hand, researchers are often unaware of the information needs of service agencies, and university-based researchers in particular may not have an adequate understanding of the nature of the service setting. Despite the clear opportunities for mutually beneficial collaborative relationships, the number of success stories is somewhat limited.

An important problem is that there are few effective venues for communication linking the research and service provision communities. It is not uncommon for researchers to resist participation in fora that attract service providers, because it is felt that the audience is insufficiently equipped to participate in rigorous scientific discourse. While service providers often seek out opportunities to hear the results of new research completed by leaders in the field, they often find it difficult to understand presentations based on complex methods and subtle findings. Thus, when professional meetings bring these two groups together, there is often a basic inability or unwillingness to communicate in terms that are satisfactory to both parties. In the service sector, ambiguity and incrementalism are barriers to decision-making and implementation. While the scientific method compels researchers to declare all the contingencies, uncertainties and limitations of findings and the paths for new research, service providers are in a constant search for clear, definitive answers. The justifiable caution inherent in scientific progress does not mix well with an environment where choices must be made regardless of the inadequacy of evidence. The deinstitutionalization of mental health services in Canada provides a good illustration of this, given the lack of resources and preparation for community-based care. Similar concerns are being raised today in the movement toward community-based care for the elderly (e.g., Rosenthal, 1994).

Aside from communication difficulties, the issue of timeliness in submission of final results is a frequent source of difficulty between these partners. Decision-makers in policy formation and service delivery frequently need information within extremely tight timelines. This sometimes leads to unreasonable demands on a research team and an inability to pay adequate attention to operational issues in the execution of a research program. More often it results in the adoption of research methods that are inadequate to address the questions of primary interest to decision-makers. For example, an agency may wish to evaluate the cost-effectiveness of its services, but only has sufficient time for a cross-sectional study of a small sample of clients. The researcher is then caught in a position of having to make unambiguous statements based on ambiguous data. Expressions of concern regarding the weaknesses of a particular evaluation methodology are often seen by service providers as indications of excessive rigidity or self-interest in the pursuit of publications. An investigator may be unwilling to make definitive statements or to undertake the research at all. As a consequence, the researcher may have foregone an opportunity to conduct work with

direct practice or policy implications, and the service provider or policy-maker may make decisions based on a false sense of security.

The primary task of researchers has been to identify relevant questions, prepare a methodological framework to examine those questions, compile and analyse appropriate data and interpret results based on those data in a manner that provides answers to the initial questions. The specific response to those answers through policy formation and service delivery has been the responsibility of government and service agencies. Despite the well-known mantra of program evaluation that all parties must have at least modest involvement in all phases of the enterprise, the translation of research into policy and practice has typically remained a discrete, two-step process. Researchers tend to not be involved in decision-making after study results have been reported, and service providers often eschew the technical details of research in favour of summaries that are oversimplified.

Further problems arise with respect to the interests and priorities that each group holds for health outcome evaluation. For example, the primary focus for service providers may be the evaluation of programs and services and on-going monitoring of the status of clients and personnel. There may be little interest in the application of evidence from these activities to the broader state of knowledge. From the perspective of government, health outcome data may be of particular interest for purposes of regulation of funded agencies and for decisions regarding resource allocation. The primary interest for researchers may include the examination of underlying principles governing health and aging. Hence, the nature of questions to be studied, the depth of analysis, and the scope of research may vary substantially depending on whose specifications define the parameters of the evaluation. Given that different interests are often pursued by different partners, it would be extremely helpful for health data collected as part of normal activities to have multiple uses in addressing multiple types of questions. This would reduce redundancy, cost and burden on agencies and their elderly clients. It may also be possible for different applications to complement each other. For example, if assessment data were used for clinical and funding purposes, funding systems could be designed to provide incentives for positive health outcomes.

An examination of trends in the service sector's information needs shows that the agenda is often dictated by the business community, rather than by researchers from other disciplines. For example, the rapid expansion of interest in Continuous Quality Improvement (CQI) initiatives and benchmarking has been driven mainly by a perceived resonance between service provision in commercial industries and the activities of health and social service agencies. Initiatives in quality improvement often adopt the language of evaluation research, but the implied authority of findings from such projects is not necessarily based on a sound methodological foundation. Health and social scientists have been quick to rebuff such projects and often choose instead to focus on broader studies with less opportunity for application. In so doing, they are perceived as being insensitive to or uninterested

in the information required by service providers.

The increasing emphasis on economic evaluation is a further source of strain. For some, the primary interest in health outcome evaluation is to identify a means of attaining better outcomes. For others, the reduction of expenditures is the main goal. There is often a great deal of discrepancy between what is currently achieved in service provision, what is possible to achieve with more, less, or the same resources, and what must be achieved in order to reach an acceptable level of population health. In a climate of fiscal restraint, there is pressure for service providers to give pre-eminence to budget reduction. However, health and social scientists may continue to focus only on maximization of health outcomes. Coupled with the absence of effective communication venues, these differences may only serve to widen the gulf separating these groups.

Conceptual and Methodological Issues

A number of conceptual and methodological issues pose challenges for the translation of research into policy on health outcomes for the frail elderly. With respect to conceptual matters, little thought has been given to the nature of desired outcomes for the frail elderly or to the theoretical framework that best applies to the manner in which those outcomes may be realized. Primary methodological issues relate to question formulation, correlation vs. causation, error estimation, the measurement of health outcomes, and the structure of data collection procedures.

The fundamental question for policy formation regarding the frail elderly in institutions and communities is: What are the desired outcomes to be achieved? For young individuals with acute illnesses, a return to the level of function prior to the illness and the eradication of pathology is the typical health goal. If this outcome is the criterion against which interventions are evaluated, there can be no acceptable outcomes for individuals with Alzheimer Disease or Multiple Sclerosis. This question also arises in the definition of interventions. For example, some rehabilitation professionals would argue that "rehabilitation" includes only interventions that result in an improvement in function over a relatively short duration.

Nonetheless, convincing cases can be made that other health outcomes are appropriate for this population. If restoration of complete independence is not possible, the prevention of decline and the maintenance of a stable level of function could be indicative of a successful intervention. In the case of inevitable decline, it may be reasonable to focus on slowing the *rate* of decline. Moreover, it may not be possible to affect all aspects of functioning, but optimization of specific areas (e.g., cognition) and avoidance of pain may have a profound effect on well-being.

There is a paucity of theoretical models regarding determinants of health relevant to this population. The health beliefs model (Sarafino, 1990) is a common staple of the health promotion literature, but it would be difficult to apply broadly in institutional settings. For instance, it provides little insight into why some patients with dementia have relatively better out-

comes than others.

The health promotion literature has begun to address the general elderly population (e.g., Berg & Cassells, 1992), but little has been done to make it relevant to the frail elderly. Indeed, one might argue that agism is a serious problem in health promotion and there is "tyranny of health" that regards illness and disability in old age as the failures of individuals (Fitzgerald, 1994). Not only is there a bias to consider the young as the main target audience for health promotion, but it is often argued that the elderly are not suitable candidates for specific types of health promotion. For example, despite growing evidence to the contrary, a number of authors have suggested that smoking cessation programs are inappropriate for older adults (e.g., Bliss, 1988). One might argue that health promotion is characterized by some level of elitism given that the costs of health promotion may be evaluated in terms of the productive contribution of its recipients. Given that the elderly are generally not part of the paid labour force, they are often seen as having diminished productive value.

If there is debate about the well elderly, what does health promotion have to offer the frail, the chronically ill, and the dying? Perhaps the answer lies in the recognition that different outcomes are relevant for different populations, and different risk factors may need to be addressed as threats to those outcomes (Black & Kapoor, 1990). For example, in palliative care one could argue for a health promotion program that aims not to extend life, but to alleviate pain and to increase autonomy to allow the individual and his/her informal social network to attend to end of life decision-making. The scope of health promotion may be broadened to include not only quality of life, but also quality of dying.

The task that follows conceptual and theoretical development is to measure health outcomes in a valid and reliable manner so that evidence-based practice and policy formation is given a solid foundation. There are a number of ways that data on health outcomes may be obtained for the frail elderly, and each has strengths and limitations. Self-report measures have the advantage of providing a direct measure of the patient's assessment of his/her condition. Despite the obvious appeal of such a measure, a substantial literature debates the accuracy of such subjective measures compared with objective measures (e.g., Chipperfield, 1993; Liang, 1986; Strain, 1993). These concerns can only be amplified among the frail elderly. Even if it can be assumed that subjective measures reflect the state of health of an individual, it cannot be assumed that the experience of patients able to report their subjective views reliably necessarily generalizes to the experience of patients unable to do so (e.g., because of impaired mental status), or that generalizations can be made from one setting (e.g., nursing homes) to another.

In recognition of the inability of some patients to respond in a valid and reliable manner, some researchers have used proxy responses to serve as substitute ratings. Again, a number of studies scrutinize the correspondence between proxy and individual ratings (e.g., Berlowitz, Du, Kazis, & Lewis,

1995), but the frail elderly probably pose a special problem. Among community-based individuals, one has some assurance that study participants and their proxies have some commonalities in their day-to-day experiences. However, for institutional residents, the proxy generally evaluates the experience of the patient from a different perspective. There may be some areas where proxy and patient views correspond closely (e.g., operational questions on the frequency of cleaning by housekeeping staff), but in many other areas one cannot assume that patient and proxy responses can be equated (e.g., perceptions of one's sense of dignity). The utility and application of proxy data therefore depend on the nature of the questions being asked.

Direct patient interviews and proxy interviews have additional costs, because they involve the collection of new data that are not necessarily relevant to the day-to-day functions of the service organization. This increases burden and stress on the patient or proxy and necessitates careful design and execution of an appropriate research protocol. Ethical considerations arise when individuals are interviewed for reasons of no direct benefit to them. Consequently, there has been interest in the use of patient records for research and evaluation purposes (Carpenter & Bernabei, 1995). There are numerous benefits related to cost and time savings in using these records, and secondary analysis can be done in an unobtrusive manner. Ethical and privacy considerations may be addressed in advance with appropriate policies and procedures. However, there are often serious problems regarding the completeness, comprehensiveness, reliability and validity of current service records. Many agencies rely on unstructured, open-ended narratives to track the progress of their clients. These are rarely useful for research aimed at evaluating the effects of policy initiatives or clinical interventions.

Another means of obtaining health outcome data for the frail elderly is the use of standardized assessments (Challis, Carpenter, & Traske, 1996). These tools often have known measurement properties as a consequence of on-going research on reliability and validity. Assuming that adequate standardization of the assessment strategy is achieved, it becomes possible to compare patients, agencies, and jurisdictions. The main limitation in this area is the general lack of assessment information as part of normal service delivery. For example, although the evaluation of mental status is fairly advanced, it is still uncommon for such information to be part of the standard client record. Standardized assessments tend to be restricted to a few clients at specific times of entry to the health care system. A second problem is the tendency for these assessments to be relatively narrowly focussed on biomedical, functional, behavioural, and/or cognitive measures. There is a clear need for a move to a broader approach that includes an emphasis on the social aspects of patient life (Zussman, 1993).

The structure of data collection in institutions and community-based agencies is also problematic. In order to conduct a reasonable outcome evaluation, longitudinal data are essential. Such evaluations should empha-

size the study of events, transitions, and trajectories of change, rather than states at a single point in time. For example, the problem of confounding by indication (i.e. a close correspondence between the indication for a drug and the unanticipated consequences of its use) is a common concern in pharmacoepidemiology that can only be addressed effectively with longitudinal data. As another illustration, Cohen-Mansfield, Werner and Reisberg (1995) show the need for information on the temporal order of cognitive and functional loss in order to plan for effective care. Hence, regardless of the means of measuring patient characteristics, there is a clear need to allow for record linkage to follow individual changes over time.

Limitations in Knowledge in Evaluating Health Outcomes

Although partners in the care of the elderly have been emphasizing the need to evaluate service delivery, this work remains in its infancy. Many gaps in knowledge hinder policy formation, but one of the more serious problems is the lack of comparable data across programs, agencies, sectors and jurisdictions. A consequence of the absence of comparative data has been the propagation of untested truisms about the effectiveness of certain models of service provision and claims about the practice patterns in different regions. In part, this is the result of a lack of standardization in the data collected in different areas, even though service providers tend to examine similar client characteristics when assessments are done (Challis, Carpenter, & Traske, 1996).

Where databases comprising common elements have been compiled, the data may not be accessible to the research community with the expertise to conduct sophisticated analyses. Reports prepared by the agencies holding the data tend to be descriptive summaries and general overviews rather than in depth investigations. In some regions, these data are used only for basic administrative purposes.

In conducting comparisons within Canada and between Canada and other countries, it is extremely important that data on individuals rather than service providers be used. For example, the terms "nursing home" and "home care" have vastly different meanings between provinces and between countries. If one intends to compare how effective treatments in community and institutional settings are across jurisdictions, it is important to be confident that equivalent services are being compared.

The evaluations of interest to service providers are often restricted to single agencies or institutions. However, for many policy questions the evaluation of systems rather than single providers is of greater interest. For instance, inclusion of multiple organizations allows for the replication of findings across settings and for a greater generalizability of findings to the broader population of frail elderly individuals in communities and institutions. Moreover, if the aim is to identify the needs of the frail elderly with specific characteristics, the research must allow for the detection of those individuals who may reside in different types of settings. For example, Canadians with mild cognitive impairment, a number of behavioral distur-

bances, problems with incontinence and some level of disability can be found in acute care hospitals, home care settings, nursing homes and chronic care hospitals. If one wishes to evaluate the effectiveness of specific interventions for this type of individual, an approach that incorporates eligible participants regardless of their place of residence should be favoured over studies of single agencies or institutions. (Although sometimes the effectiveness of an intervention can be evaluated by studying single agencies or institutions.)

Use of the Minimum Data Set (MDS) for Comparing Health Outcomes in the Frail Elderly

A proposed solution to the many barriers to linking health outcomes research to policy formation is the establishment of a national clinical data base that incorporates standardized assessment information from individual records for frail elderly persons in institutions and community-based agencies. It is widely agreed that comprehensive geriatric assessment (CGA) is a key to good quality care of the elderly (Rubenstein et al., 1988). Standardized assessment can provide information about indicators of need, and changes in assessment items can act as indicators of outcome. CGA has also been used to demonstrate improvements in outcome of health care in a variety of settings (Stuck, Weiland, Adams, & Rubenstein, 1993; Phillips, Hawes, Mor, Fries, & Morris, 1996). Of course, this requires a degree of uniformity across agencies in mode of assessment. However, this does not preclude agencies from adding specific questions of special interest to them.

Assessment is carried out routinely at many levels by a wide range of individuals from different disciplines involved in the care of the elderly. A review of assessment instruments from 50 local authorities in the United Kingdom showed that of 33 assessment domains, 39 per cent were not covered in one-fifth of assessments, and 20 per cent were covered by fewer than one-half. Standardized items were rarely used. Variability in assessment is therefore high, and comparability and the capacity to generate standardized information, low. Only 24 per cent were used jointly by health and social services (Challis et al., 1996). Poor assessment may lead to poor care targeting and delivery, and certainly will present difficulties in determining benefits of care. Using a standardized assessment instrument for assessment of care need could enable better monitoring as well as improve the outcome of care of the elderly.

While at first glance implementation of standardized assessment may appear to be an exceptionally difficult goal, international experience using the Minimum Data Set (MDS) provides clear evidence of an appropriate model (Fries et al., in press). The MDS is a standardized assessment approach for use in long term care settings that was originally developed in the United States. A national resident assessment instrument was mandated under the 1987 *Omnibus Budget Reconciliation Act* as a means of enhancing the quality of care in American nursing homes and enhancing

the quality of life of residents in those facilities. In the U.S. alone, approximately \$6.5 million and almost ten years of research have been devoted to the development of a clinical instrument to be used for multiple purposes. A number of papers have been published concerning the reliability and validity of specific items and scales included in the MDS and on the use of the MDS to examine a broad range of issues in institutional care (Blaum, Fries, & Fiatarone, 1995; Hawes et al., 1995; Mor et al., 1995; Voekl, Fries, & Galecki, 1995).

The MDS is used in nursing homes throughout the U.S., and has recently been adopted for use in other countries (e.g., Iceland, Denmark, Japan). To date, large scale research projects based on MDS are underway in 16 countries, including Canada and the U.K. In Ontario, all patients of chronic care hospitals are assessed using the MDS on a quarterly basis, as of July 1, 1996.

The MDS is first and foremost a clinical instrument to be used in the care of the frail elderly and non-elderly adults with disabilities. The standardized assessment approach includes a series of Resident Assessment Protocols (RAPs) that use a variety of indicators to trigger clinical reviews and care planning activities in 18 different domains (Morris et al., 1996). In addition to the individual items in the MDS, these RAPs may be used as health outcome indicators in monitoring individual treatment and in program evaluation. There are also a number of clinical scales that can be used to evaluate patient functional ability. For example, the MDS Cognitive Performance Scale (CPS) has been shown to be highly reliable and strongly correlated with industry standards such as the Mini-Mental State Exam (Hartmaier, Sloane, Guess, & Koch, 1994; Morris et al., 1994).

Data from MDS assessments in a number of countries have been collated on the University of Michigan Assessment Archives Project (UMAAP) database at the University of Michigan. This database illustrates the potential for comparisons using standardized data in which definitions, assessment guidelines, assessor skill levels and training methods are comparable in different countries. Table 1 shows that the prevalence of fecal incontinence (an accepted indicator of quality of care) in Denmark is lower than in Japan, Pennsylvania and Toronto in nearly all patient groups that were studied. The differences are greatest in the most physically dependent (high level of functional impairment and totally dependent in bed mobility) and the severely cognitively impaired (cognitive performance scale score of 5+) categories. Important questions arise about what is in the health care service in Denmark that leads to such dramatic apparent differences. Table 2 shows prevalence of patients with grade 3+ pressure sores. The figure in Toronto is three times that of Denmark, which in turn is three times that of Japan. The low prevalence in Japan is seen in all patient groups except those with low functional impairment. There are, of course, many explanations for these findings, but attention should be given to possible differences in patient management. While some of the overall prevalence rate differences are explained by variations in the severity of impairment of patients

Table 1
Percentage of patients with fecal incontinence in four populations using the Minimum Data Set

	<i>Japan 1994</i> (<i>n=2525</i>)*	<i>Copenhagen 1994</i> (<i>n=3442</i>)*	<i>Pennsylvania 1993</i> (<i>n=26559</i>)*	<i>Toronto 1995</i> (<i>n=929</i>)*
<i>Bed Mobility</i>				
Totally dependent	83.1	56.7	86.0	67.4
Not totally dependent	16.0	15.4	30.5	34.8
<i>Cognitive Performance</i>				
<i>Scale</i>				
CPS score 2+	50.5	31.0	58.5	60.8
CPS score 5+	78.6	44.6	81.6	69.7
<i>Functional Impairment</i>				
Low	4.4	8.9	8.4	7.5
High	71.1	42.8	63.0	59.0
Total with fecal incontinence	31.4	22.4	43.2	53.0

Note: * For Tables 1 and 2, see Carpenter and Bernabei (1995) for a detailed description of the methods used for the data from Japan, Copenhagen, and Pennsylvania and see Metropolitan Toronto District Health Council (1995) for a summary of the methods for the Toronto data. The Japanese data are courtesy of Professor Naoki Ikegami, the Copenhagen data courtesy of Professor Marianne Schroll, and the Pennsylvania data courtesy of Professor Brant Fries. Functional impairment is based on the ability to perform four different types of activities of daily living. Higher scores on the Cognitive Performance Scale (CPS) indicate more severe impairment in cognition.

Table 2
 Percentage of patients with grade 3+ pressure sores in four populations using the Minimum Data Set

	<i>Japan 1994</i> (n=2525)	<i>Copenhagen 1994</i> (n=3442)	<i>Pennsylvania 1993</i> (n=26559)	<i>Toronto 1995</i> (n=929)
<i>Bed Mobility</i>				
Totally dependent	1.7	4.6	7.7	6.2
Not totally dependent	0.1	1.0	1.6	3.0
<i>Cognitive Performance Scale</i>				
CPS score 2+	1.3	2.1	4.7	4.7
CPS score 5+	0.2	1.4	2.3	5.3
<i>Functional Impairment</i>				
Low	0.7	0.5	0.6	2.8
High	1.1	3.3	4.4	5.0
Total with grade 3+ pressure sores	0.5	1.6	3.0	4.8

in general nursing home beds compared with chronic hospital beds in Toronto, important differences persist across countries after adjusting for patient characteristics. For example, care environments, staffing arrangements, and patterns of family involvement vary considerably. The next step in research should be to conduct much more detailed comparisons using multivariate analyses to control for combinations of patient-related variables prior to drawing any definitive conclusions about international variations. Nonetheless, what makes MDS exciting is that it gives researchers the ability to do precisely that type of meticulous clinical comparison across disparate populations.

The typical approach to using the MDS is to conduct full scale annual assessments, briefer quarterly assessments and full assessments in the event of major clinical changes. Provided there is adequate record linkage, the MDS system therefore allows for the evaluation of longitudinal changes in health outcomes and other patient characteristics. In this way, the MDS is ideally suited to provide data on trajectories of change when incorporated into normal service provision. An evaluation of the impact of using the MDS three years after its introduction to the U.S. has shown a reduction in decline in abilities of activity of daily living over time, a reduction in the prevalence of pressure sores, reduction in the use of restraints, and a dramatic reduction in rate of transfers to hospitals. Transfers to hospitals were reduced by 15 per cent among the non-cognitively impaired and by 25 per cent among the cognitively impaired, with no increase in six-month mortality. In addition, there were marked improvements in the completeness and accuracy of assessments and care plans in 240 participating nursing homes (Phillips et al., 1996). It is difficult to attribute all of these outcomes to the introduction of the MDS, because they may have been caused, at least in part, by other important changes in the U.S. health system, patient characteristics or treatment patterns. Nonetheless, the results are consistent with what one would expect to occur when a better understanding of patient needs is achieved.

Aside from their obvious clinical applications, data from the MDS have been used in a number of other ways. Fries and his colleagues have developed an algorithm that uses MDS items to measure resource intensity based on Resource Utilization Groups (RUG-III) (Fries et al., 1994). The RUG-III system is used in a number of American states and other countries to allocate health resources, and it is currently under consideration for funding long term care in Ontario and Saskatchewan (Carpenter, Main, & Turner, 1995; Hirdes, Botz, Kozak, & Lepp, 1996; Ikegami, Fries, Takagi, Ikeda, & Ibe, 1994; Ljunggren, Fries, & Winblad, 1992). Another application of MDS is the development of Quality Indicators (QIs) through research by Zimmerman and colleagues (Zimmerman et al., 1995). In this work, specific MDS items can be used to flag potential problems with the quality of service delivery. The information is of interest to planners who aim to improve the quality of care in an institution and to regulatory agencies as a screening tool. Aside from these clinical, administrative, and regulatory applications,

the MDS provides fertile ground for applied research aimed at addressing substantive questions regarding health outcomes for the frail elderly.

A number of new instruments related to the original MDS for institutional settings are now under development. Field testing for reliability and validity assessment was recently finished for a home care version of the MDS. A casemix system for use in home care settings relating person characteristics to care costs similar to RUG-III is under development. A version of MDS for acute care is in early stages of development, and a feasibility study to develop a version for use in psychiatric settings is underway.

The MDS is designed for use in routine practice and has even been used as the basis of a training program in care of the elderly (Landi et al., 1994). It allows researchers, service providers, and policy makers to speak a common language by focussing the terms of discourse on a standardized set of items with known measurement properties.

The efficiency gained by the use of a common data base for secondary analysis need not come at the cost of reduced reliability, validity, comprehensiveness, or relevance. Repeat assessments over time may be used to show the impact of service intervention at the individual level or policy changes at facility or regional levels. Different partners may use data for their own purposes to address questions of interest to themselves, but it is also possible to understand the evidence used by another partner for a different purpose. To the extent that the newly developed versions of MDS are implemented in other sectors, it may be possible to conduct direct comparisons of the experiences of individuals with like characteristics living in communities and institutions in different jurisdictions. Hence, it will be possible to conduct true system level analyses using data already gathered as part of normal service delivery and to address key elements of the critical question "who gets what, with what consequences".

New and Unresolved Issues

If MDS is to be implemented broadly in Canada for use by partners from the service, government, and research communities, several issues must be addressed. The main areas of concern involve issues of confidentiality and data access.

Problems of maintaining patient confidentiality are well-known to all the partners interested in health outcome measures. It is already possible to compile and report these data in a way that specific individuals cannot be identified. However, it should be recognized that the patient is not the only individual whose confidentiality is at issue. Given the ability to use MDS to derive quality indicators, there will be considerable interest in comparing the relative performance of facilities or clinicians. Careful consideration must be given to how this information should be reported in a constructive manner. Simply suppressing facility or clinician level data is not helpful, because there is an urgent need to look at both individual level and

structural variables that influence health outcomes (see, e.g., Spector & Takada, 1991). Fundamental questions about the effects of different models of service delivery cannot be examined if data on those models are unavailable.

The question of confidentiality inevitably leads to the question of data access. A reflexive response is to restrict access to service agencies and the agencies compiling the data, but the exclusion of the research community can only be an impediment to linking research and policy. For example, the Ontario government has compiled data from long-term care facilities using the Alberta Resident Classification System since the early 1990s. To date, there has been virtually no published research based on these data, and their use has been restricted to operational reporting. In several countries the MDS has already been used effectively in multiple ways by multiple partners, and there is no reason why this experience cannot apply to Canada. One important threat is proposals in privacy legislation that could restrict access to such data to exclude university-based researchers. If implemented, this could only serve to widen the gulf between research and policy.

A further point relates to the timeliness of data access. The various partners needing information from a national data base based on MDS have different expectations for timeliness. Service providers usually need basic information about the needs and problems affecting their clientele on an almost immediate basis. Risk managers, for example, need information on falls on a weekly or monthly basis to monitor the need for intervention. For policy-makers, the data must be available in time to provide information for proactive policy development. Hence, the turnaround time should not be excessive. For researchers, data must be relevant to the current context, but the search for underlying principles means that one aims to identify associations that are relatively stable over time. Therefore, data that are one year old are typically more than adequate, provided that there has not been radical change in institutional or community based service delivery.

Summary and Conclusions

Many factors create barriers to closer links between policy and research on health outcomes among the frail elderly. Some are the consequences of problems in the partnerships among service providers, researchers, and policy-makers. Others arise because of inadequate attention to theoretical and conceptual development and/or methodological problems inherent in current approaches to data collection. Finally, the emphasis on segments of the health and social service system has constrained knowledge to pieces of the puzzle without yielding a sense of the overall puzzle itself. The development of a national data source based on the MDS has the potential to reduce, if not to eliminate, many of these barriers. There are models of effective implementation of this system to move toward evidence-based practice in other countries that can be applied to the Canadian context. Given appropriate attention to issues of implementation and access, there is an oppor-

tunity to dramatically improve the ability of research on the frail elderly to have a meaningful impact on the development of policy at the national, provincial, and regional levels.

Note

- 1 There is considerable debate in the current literature on the conceptualization of frailty. For the purposes of this paper, the term "frail elderly" is intended to be broadly inclusive of individuals in community and institutional settings who are at substantially elevated risk of decline in health or functional ability because of a combination of physical, social, psychological and environmental factors. For example, an 85-year old widow with serious visual impairments and osteoporosis may be considered "frail" because of an elevated risk of hip fracture.

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