Using research to improve long-term care

SPECIAL ARTICLE

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ABSTRACT

Research and evaluation play important roles in moving forward the underlying science of long-term care (LTC). The definition of the intervention is less precise in LTC than in clinical care. Long-term care research addresses both efficiency and effectiveness. Research can test whether a programme works or what elements are effective. The LTC research model has five steps: (1) identify a researchable problem; (2) develop a conceptual model; (3) operationalise the model; (4) develop the analysis plan; (5) present the findings. Empirical findings should drive future LTC but other factors must be considered as well.

Key words: Aged; Long-term care; Research

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GENERAL PRINCIPLES

Although some aspects of decisions about long-term care (LTC) are based on philosophical and social concerns, like any other service, many LTC decisions need to draw on empirical information whenever possible. Research and evaluation thus play important roles in moving forward the underlying science of such care. Admittedly, other forces also play a major role in shaping LTC programmes. Politics, traditions, entrenched self-interests, and strongly held beliefs all play their parts. Information that contradicts many of these will have a harder time being accepted, however strong its scientific base. Changing scientific or social paradigms has never been easy or quick.

Research can play several important roles in improving LTC:

1. It can introduce new ideas about the art of the possible. It can raise expectations about what can and should be achieved. Empirical data can challenge widely held beliefs about what kinds of care can be mounted effectively. It may be able to overcome long-held prejudices about what sorts of care are appropriate for frail older persons and what the true risks associated with giving them more freedom and choice are.
2. It can evaluate programmes that purport to offer new advances to see if they achieve their goals, or even more importantly, socially important goals.
3. It can create new tools to assess problems and to guide solutions.
4. It can identify unmet or inadequately met problems.
5. It can identify more efficient ways to deliver care. It is important to remember that one should not talk about efficiency until effectiveness has been demonstrated. Discussions about efficiency are too often really about cost, but cost-effectiveness requires effectiveness.[1]

Long-term care research shares much in common with other forms of health services research. In contrast to much clinical research, the definition of the intervention is less precise. In a drug trial, for example, one would test a specific dosage of the drug under consideration for a prescribed duration (these factors would presumably have been tested in prior small-scale studies). In LTC research, by contrast, the nature of the intervention is often vague. Neither the dosage nor the duration of care is well specified. It is not necessarily consistently administered. Some parties may be enthusiastic and some reluctant. Double-blind designs are rarely, if ever, possible.

The specificity of a LTC intervention is often much less than that for a drug or a medical procedure. No one would think it rational to ask if penicillin cured disease. But somehow, similarly general questions about LTC's role in preventing nursing home

admissions or hospitalisations for an undifferentiated group of clients seem quite acceptable.

Long-term care research can address problems of efficiency and effectiveness. Ordinarily one would first want to know if a service is effective, and then go on to see if it can be efficiently delivered. However, financial pressures may make it imperative to test only these approaches that are a priori viewed as being affordable, thereby constraining the generation of new knowledge. Or the only way to get care providers to participate in a new venture may be to pay them at a rate that at least assures them they will not be financially penalised, thereby limiting the options available or the ability to generalise to what would happen in an operational programme.

Many have criticised demonstration programmes as being too artificial to serve as the basis for programmatic reform. Providers (and perhaps even consumers) are unwilling to buy into what is seen as a temporary programme sufficiently to make the basic changes in practice that would be necessary to bring about the reforms that need to be tested.

Conversely, demonstration programmes may suffer from just the reverse as well. Those providers who join in may make a substantial financial, organisational, and emotional investment in the changes. As a result they become wed to them. When the evaluation results fail to show that the innovation has produced much of substance, they have already formed a strong pressure group to lobby for continuation of the ineffective programme. They will hire their own advocates and experts to challenge the findings creating, at least, confusion.

Programme evaluation is an important part of scientific advancement in service industries, but it is fraught with peril. The timing of the assessment is crucial. One is always forced to balance the need for information in order to make policy decisions about continuation and expansion against a desire to test a fully developed programme. Often the evaluators are asked to provide an assessment of a programme that has barely been established. Programmes take time to get started. The costs and the effects of a newly established programme may be quite different from one that has been in operation for a while. Newness can present artificial advantages and liabilities. Among the latter are the needs to shake out the bugs in a new concept and to get it operational. Development is more expensive than operating at a steady state. On the other hand, those that undertake new ventures are usually pioneers who are determined to make things work despite the obstacles. The programmatic settlers will be more rule-driven and less motivated to do whatever it takes to make it work.

Policy makers want results quickly. Once they have invested in a programme, they have little patience to wait for it to mature to the point when it can be properly evaluated. On the other hand, some policy makers view demonstration programmes as a way to avoid making real programmatic changes. Faced with a cry for reform, they temporise by calling for demonstrations. The less successful these demonstrations or the more controversial their results, the longer they can avoid facing the hard choices. Frequently demonstration programmes become advocates for their own continuation. Long before the evaluation results are available, the demonstration programmes have been actively lobbying for their survival. An evaluator raising questions about a programme's effectiveness may have to face harsh criticism and political manoeuving from those with a stake in the programme's continuation. Even the policy makers may have an investment in not acknowledging a programme's poor showing lest such results reflect poorly on their initial support.

Research can help to change the way things are done in LTC. Perhaps the most visible manifestations are the creation of new tools. Providing practitioners with the means to measure a construct greatly enhances the likelihood that that construct will be addressed.[2,3] Perhaps no tool has been as influential as that used to measure activities of daily living.[4,5] Although no single tool is predominant, the availability of measures for this construct (and its close cousin, instrumental activities of daily living) has provided a framework and a language to discuss functioning. It has done for LTC what Freud did for psychiatry. Even detractors are forced to use the language and descriptors in their attacks.

Research can also point to new ways of thinking about things. For example, much of the recent research has challenged the entrenched ideas that linked services to sites.[6] It has shown that the same services can be provided in different settings. It has

Table
Quasi-experiment versus randomised controlled trial

Quasi-experimental	Randomised controlled trial
Suggestive associations	Permit causal modelling
Treatment effect inferred	Design isolates treatment effect
Selection bias possible	Random assignment
Post hoc case mix adjustment	Inclusion/exclusion criteria
Treatment variation	Tight treatment protocol

offered a means to focus attention on the outcomes of care as a way of comparing the effectiveness of these same services across sites.

Because most of this research is quasi-experimental, it is always open to the challenge of selection bias.[7-9] This term means that different types of people may opt for (or be assigned to) different service locations. Careful attention to the comparability of the various service recipients and application of sophisticated statistical devices must be employed to counteract this possibility.

BASIC PRINCIPLES OF APPLIED RESEARCH

Long-term care has a number of elements in common with various forms of applied research. Each of these is addressed in more detail elsewhere[10]; however, a few general statements about the five basic steps involved in conducting such research can be offered here.

Identify a researchable problem

This would seem to be a simple admonition, but it is harder than it seems. The problem must be clearly stated and its components assessable. The role of intervening factors and the population targeted must be made explicit.

Develop a conceptual model

This model should show the expected relationship between the characteristics that define the study population and the outcomes it is expected can be achieved. It should be possible to draw a simple diagram that illustrates the logic of the perceived model. The role of intervening factors and their potential influence, either directly or indirectly, should be shown. Other factors may influence the effect of the intervention indirectly, such as by influencing the likelihood that it will be followed or by impeding its full implementation. Thought should be given to the role of interaction; that is, whether a given variable acts directly on the outcomes or affects the way another variable affects the outcomes. For example, does a given type of LTC work better for older persons with no informal support than for those with such support? In this instance, informal support is an interacting variable; its effect is best perceived through its influence on the effect of another variable (LTC).

Operationalise the model

This step includes several important components:

Determine the study design

The most common way to test interventions is to use either a randomised controlled trial or a quasi-experimental design. The latter is more often appropriate to LTC research because of ethical and financial constraints, but the randomised controlled trial (RCT) should be actively considered whenever possible. The basic difference between the two designs is in the assignment to treatment group. In an RCT the assignment is not under the control of those giving or receiving the care. Therefore the analysis of quasi-experimental studies usually requires more sophisticated statistical methods. Too often investigators may assume that just because they use random assignment only simple statistics are needed. Such an interpretation may compromise learning all that is possible from a closer analysis of subgroups or a recognition that the effects of various factors should be adjusted for, even in an RCT. The **Table** summarises some of the other differences between the two approaches. In general, the RCT trades off generalisability to obtain greater internal validity.

Define variables

Both the dependent and independent variables must be specifically operationalised. How will they be

measured? Wherever possible one should use defined and tested measures rather than developing one's own. However, it is essential to actually examine these measures to be sure that they measure what they purport to measure and that they fit the situation where they will be used (i.e. cover the right spectrum of measurement).

Identify data source

Is new data collection needed? Can administrative data or records be used? Will you need observations or interviews?

Determine sampling

Who will constitute the control group(s)? How will they be identified and selected? What biases may be involved?

Develop the analysis plan

The analysis should be specific to the research questions. The actual techniques used should be explicitly described. They should match the nature of the data; different statistical tests are used for categorical and continuous data. The sophistication of the analysis may vary. At a minimum, multivariate analysis is likely to be needed, but new approaches, such as hierarchical modelling, which examine the effects of nesting (where one class of variables is actually a subset of another, e.g. residents are nested inside nursing homes; one would want to test the effects of an intervention recognising the effects on both the home itself and the individual residents), should also be considered.

Present the findings

The presentation needs to fit the audience. It should include a section on the implications for practice and one on implications for the larger field. Researchers need to walk a fine line between so much self-criticism that the value of their findings is rendered moot and failing to acknowledge the inevitable limitations of their study.

SPECIAL ISSUES IN LONG-TERM CARE RESEARCH

Human subjects

Because LTC research is often conducted with frail individuals, many of whom are cognitively impaired, it is hard to obtain informed consent from the subjects. Much of this consent must come from families, who may be very protective of their relatives. Most of this research does not offer any substantial risk, but neither does it confer much benefit. The motivation to participate is largely one of helping others yet to come. This motive may appeal more to older persons than their families, who may be reluctant to do anything that places a strain on their relatives.

Staff reluctance

Most LTC staff see themselves as already overwhelmed. Learning a new research protocol or disrupting their routines may not be attractive. Some staff may view the presence of outsiders as threatening. They may feel concerned about corners they have been forced to cut and thus be reluctant to open themselves to observation and to criticism. Great care must be taken to establish rapport with the staff. A climate of trust must be created.

Frequently, an innovation is demonstrated by temporarily adding staff to carry it out. Once the demonstration project ends, the extra staff disappear too, and the innovation is never incorporated into the ongoing operation of the programme.[11] In other situations, attention is focussed on a programme for a period of time but then transferred to a new area of interest in the context of continuous quality improvement. If only a finite amount of staff energy is available for this purpose, the benefits may not be sustainable, and conclusions based on innovation may prove too optimistic for daily practice.

SUMMARY

Research can play a critical role in improving LTC, but it is often hard to conduct the necessary studies well. Basic principles for such research are widely available, but they must be combined with sensitivity to the practice context. Good practice should be based on empirical findings but other factors will influence what path is ultimately taken.

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