Consumers and Volunteers as Collaborators: Lessons from Rural Palliative Care Research

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INTRODUCTION

The involvement of consumers and health service volunteers in selected aspects of care planning and service delivery is evident in practice areas such as rehabilitation, palliative care and mental health services.

Health service “consumer” or lay public involvement in health research and service development can be readily legitimated, urged and even mandated in some sectors. Such involvement contributes to accountability for processes and offers some assurance to those who fund, support or have an interest in research, and for those who choose to implement its recommendations. This paper recommends that it should be axiomatic that the intended beneficiaries of research should have a meaningful say in its design, conduct and implementation.

The paper considers consumer and volunteer involvement generally, but with particular consideration of some of the implications for rural health and for rural people. Specifically, it addresses the potential role for health service consumers and volunteers in rural health research. That role is usually to serve on Project Steering Committees, Advisory Committees, Reference Groups and other mechanisms to support rural health research and service development.

RURAL HEALTH SERVICE PROVISION AS A RESEARCH ARENA

What counts as rural health research? What are its priorities, its challenges, its potential and its limitations? From what does it derive? On what does it draw and what might it contribute to research beyond that specific to rural health?

Attention to such issues is necessary if rural health researchers, clinicians, administrators, policy makers and educators are to achieve optimal rural health services, and to fulfil their collective potential to make a vital contribution to the health of rural Australians. The Australian Government has recognised the necessity to give considerable attention to the health of rural Australians and the infrastructure is being established through improved rural health initiatives, such as University Departments of Rural Health (UDRH), Rural Health Support Education and Training (RHSET), and a focus on health professional recruitment to under-serviced rural and remote areas.

Such research requires particular attention to the “context” of the conditions in which health professionals are engaged in rural and remote areas. This contextual awareness is
essential to the credibility of the research in the eyes of rural people. This is not always achievable within the scope of rural health research projects, given the demands of project budget, development and timelines. In addition, the motive to make a difference in the real world, sooner rather than later, forces changes and compromises to rural health research design. The need for service development and improvement in rural areas may be seen by communities as too urgent to await the outcomes of complex research processes.

Addressing issues, and finding a balance among competing priorities and perspectives is, in part, the motivation of the National Rural Health Alliance in construing its 2001 annual conference around practical rural health issues, with specific attention being paid to research derived from, and relevant to, rural health service provision. What kinds of research may, under current circumstances, contribute most to improving the health of rural Australians? What are the options?

Applied research

“Applied research” is research intended specifically to make a direct impact on the real world from which it derives; it is the application of research theory to real-life problems. With increasing pressure for accountability for public funds devoted to research comes, appropriately, increased pressure to apply that research to real-world problems.

Most rural health research is likely to be applied research. This paper draws on applied research in rural, clinical service provision, and seeks to distil out of it imperatives that may guide other research intended to enhance service provision in rural Australia.

Clinical research

Though taking many forms, “clinical research” can be broadly construed as that which seeks to contribute to improving the health of people by generating new knowledge and testing and trailing options. At one extreme, that may be laboratory-bench research seeking new pharmacological interventions, at the other, it may be directed to public health. Clinical research in rural health may be considered as that seeking to improve efficacy of therapeutic interventions, taking into account some of the exigencies of rurality.

Evaluative research

“Evaluative research” can be important to understanding how much difference new approaches have made to the health of rural communities. It can respond to questions of how and why such changes have made a difference, or have not made the difference they were intended to make.

Evaluative research is meaningful or worthwhile only if service modifications occur as a result of what is learned. The challenge is to mount evaluative projects that are fearless and objective external reviews, rather than self-fulfilling legitimation of what already exists.
Rural health research

Some contexts for health service provision are clearly defined and readily circumscribed. Some, like rural health, are less clearly circumscribed and amenable to the methodological imperatives of research and the usual norms for generalisation.

Similarly, some clinical specialities and geographical areas have particular difficulty recruiting and retaining staff, maintaining services, and addressing difficulties in health service access and distribution. These include palliative care\(^1\), mental health\(^2\), and rehabilitation.\(^3\)

Distribution of health services, and access to them once they exist, are dominant issues for rural health, not only in Australia, but worldwide. The 4th World Rural Health Conference in Calgary, Canada (2000) bears testament through the proportion of papers dealing with access and distribution issues. The National Rural Health Alliance conference (2001) has a similar emphasis.

THE ESSENCE OF COLLABORATION

Collaboration can be considered in terms of a purposeful interaction between nurses, clients, other professionals, and community members based on shared objectives and joint effort to achieve them. Through designated and clear responsibility much can be done to achieve agreed goals and maximise resources\(^4\). The need for collaborative approaches to health care is perhaps more important in rural areas than in high population areas, where referral and consultation options are more readily available. Palliative care is one clinical domain in which interdisciplinary and intersectoral collaboration are essential.

Collaborators work with other people to achieve shared understanding of the issues and goals in order to then determine and realise those objectives and goals. In the 1970s and 1980s teamwork and leadership were big issues in health care. In some ways collaboration is latter-day teamwork.

Street\(^5\), outlining the patient-centred context in which collaboration may occur between doctors and nurses, says:

> the unspoken value by which nurses judged the team effectiveness was in terms of the capacity to collaborate with the medical staff to bring about the best result for the patient.

CONSUMER INVOLVEMENT IN PALLIATIVE CARE

While it is easy to assert the merits of and to legitimate collaborative approaches, it is more difficult to say what form that involvement should take in order to make it worth the time of the consumer, volunteer or representative of the public interest. One practicality is how to involve the consumers or volunteers in such a way that their involvement is worth the effort.\(^6\)
For the purpose of this paper, the consumer is the recipient of care from the palliative care team. Partners and loved ones of those having, or having had, palliative care are included in this definition.

Many people in these consumer representative roles have considerable relevant background and experience. Researchers need to consider how to get the best advantage from consumer experience of palliative care. If the consumers themselves are not able to meaningfully contribute, one could ask why are they there?

The notion of client/consumer as collaborator

The literature on community health seems well equipped with relevant commentary on collaboration. However, little of it draws the patient/consumer into this context. An exception is Spradley and Allender in which the notion of “partnerships with communities” is canvassed.

When collaborators can be brought into a multi-disciplinary health team to plan and implement a program, the collective effort can be potent indeed. Underpinning such initiatives is the notion of building integrated and comprehensive health care systems. Similarly, the notion of partnerships with communities can add value to community health, rural health and remote health initiatives.

Nurse Practitioners, and indeed, nurses in most rural settings, can be instrumental in securing such partnership arrangements, building on established relationships with general practitioners and a defined client group. The success of programs focused on healthy communities, healthy cities, heart health and diabetes awareness are among initiatives in which consumers can take a lead role. Advisory and Action groups constituted from community members, some of whom have considerable influence in their communities, have access to adjuncts unavailable to employed health professionals.

In a “cash-strapped” and “staff-short” economy, there is a temptation for people to assess consumer involvement in the care process as “another cost-cutting measure”. Moorhouse refers to a nurse practitioner model of partnership between rural nurses and rural medical practitioners as a way of “value-adding” to existing pressured health services. Where such models of care in community settings focus on improving the level and accessibility of care available, it can work well with support from health professionals and administrators.

Motive: why get involved?

The most commonly expressed motive for becoming a “consumer advisor” is a wish to help others in similar situations. The trigger for such involvement may take three forms:

- a particularly good experience the person wants to share;
- an untoward experience the person wants to avoid other people having; and
- the wish to contribute something useful to others as a gesture of farewell to a world the person knows they are due to depart.
What works?
The valuable consumer/collaborator is the one who:

♦ makes a difference to the processes of decision making and to the outcomes reflected in health services and clinical pathways;

♦ makes a difference to the way palliative care, or other services, are provided; and

♦ is an active participant in the decision-making process.

What does not work?
The consumer/collaborator who adopts the role of:

♦ “making sure that […] untoward experience] doesn’t happen to anyone else”. This contributes to health professionals and administrators becoming awkward and defensive;

♦ either taking over or forcing ideas and perspectives; and

♦ passively observing the process, ie not contributing to the shaping of outcomes, but sitting on the sidelines watching.

Not all people holding positions as “consumer representative” in rural health-related organisations are equally useful, confident, articulate or able to put forward a strong case clearly or contribute to a sound resolution of issues addressed. Certainly, there should be no person taking up such a role “just for the sake of it” or because an organisation should be involved. This is pious window dressing. Thus it is important for the person to be known before an invitation to serve is issued. Failure to do so can result in an inappropriate appointee being on an advisory committee for some years without making significant contribution.

Maximising the potential contribution of consumers
At the other extreme many consumer representatives contribute well beyond reasonable expectations. A periodic “review discussion” between the consumer committee member and its Chair, can help reveal frustrations, identify potential opportunities for greater contribution, and bring a perspective to bear that may not have come to light in the course of normal meeting procedures. Some organisations structure genuine and effective consumer representation into their modus operandi. The National Rural Health Alliance is one such organisation.

VOLUNTEER INVOLVEMENT IN PALLIATIVE CARE

Palliative care is one area to which health service volunteers contribute regularly. Their presence in unobtrusive ways assisting, for instance, with purchase of toiletries or reading newspapers or discussing issues of the day, can impart to the hospital or health service a sense of normal engagement in aspects of the social world. This assistance is at a stage when each such discussion or experience can have special meaning to the patient as potentially one of the last they will have.
Volunteers in this way can contribute to health care agencies of palliative care clients realising what Dame Cicely Saunders expresses:

You matter because you are you. You matter to the last moment of your life. And we will do all we can, not only to help you die peacefully, but to live until you die.¹⁰

Motive: why get involved?
The usual motive for a volunteer is simply to help. Volunteers come routinely within hospital walls “doing” the flowers, or the paper run, or contributing to a collection and delivery service not requiring conditions of confidentiality or legal security. In such roles, volunteers are often regarded by service delivery staff and administrators as essential to the health care enterprise, carrying out the “little things” that are increasingly under threat, as paid service personnel reduce in number.

We think, most often, of volunteers as doing the menial and the routine; the non-clinical; as well meaning people who just like an involvement with the drama of health care. In one rural hospital I visit regularly, the same volunteer has operated a shop at the entrance for over ten years. It offers a limited range of produce, which could never be considered financially worthwhile to the hospital. However, its worth is considerable as a symbol of a community that cares for its hospital through the work of community volunteers.

Similarly, volunteers who work in palliative care services, apart from offering useful, relevant services, send to the recipients of palliative care, a potent message of care and concern at a time of considerable vulnerability for the person.

What works?
For all the projects on clinical aspects of palliative care, including its important social-psychological dimensions, research into the impact of volunteers on the course and outcome of treatment, and “end of life support strategies”, is scant. We know little about what works, how and why. Thus, palliative care support services are arranged on the basis of judgement, good and informed judgement no doubt, but done more “in faith” that it will be a good thing, rather than on the ground of demonstrated efficacy of the engagement of volunteers to assist optimal clinical outcomes.

A sense of collaborative endeavour between professionals and volunteers is essential for consumer involvement in palliative care. When the motive is to assist the hospital, rather the individuals and families, then a context arises for the emergence of cynicism and diminishing volunteer activity.

McKinnon¹¹ contends that effective collaboration requires health professionals and consumer/volunteers to develop and maintain professional working relationships through clearly delineated roles and goals. The outcome is that volunteers develop a sense of being valued for their involvement. Their growing confidence in that role can contribute to better clinical outcomes.
Wolf identifies four concepts supporting collaborative action:

- professional communication;
- unit norms;
- professional shared governance; and
- interdisciplinary relationships.

Where the collaborating partner is the patient or the volunteer, the principles are similar, though details and responsibilities are clearly different from those pertaining to professional staff.

If having a volunteer on a project management team is prompted by the “seen to be a good thing” motive, it will be insufficient to enable optimal contribution, and may deteriorate into tokenism.

This leaves the unanswered question of how to measure those clinical outcomes arising from volunteer involvement. Such outcome measures enable service providers to judge what works, and why. In this regard, collaborative health care becomes client and community focused rather than professionally preoccupied.

Is it worth the trouble?

In a health system under pressure, there are incentives to examine ways of providing effective care in creative ways, including a wider and more creative use of volunteers.

An important role of the informed and articulate volunteer is to keep the focus of the group broad, reducing the risk of becoming bogged down in day-to-day project management. The presence of non-health professionals on steering committees and advisory committees can encourage the meeting/decision-making processes to be more clear, unequivocal, focused and transparent.

Palliative care support often happens with in-house services staff and other non-professional people in the hospital or the community health context. They can develop relevant and useful relationships with those who are dying, offering them an opportunity to be themselves. They raise for general discussion, or simply en passant, things in the non-health-specific arena that may have significance to the person’s review of life’s events, trajectories, achievements and frustrations, and in doing so lend a degree of normalcy to the patient’s life.

Professional staff are rarely in a position to engage in these discussions which are peripheral to core health service delivery. Such matters may have considerable subjective significance to the person who is dying. However, paradoxically, the dying person may more readily relate to cleaning staff, porters and orderlies and other support people, the things that concern them deeply, not perhaps at a medical level, but at the important personalised level of unfulfilled life opportunities and obligations, frustrated ambition, sadness and achievements not recognised by others.

The pressures of clinical service provision often preclude the entry of professional staff into this informal territory, and the “mandated for” clinically focused discussion can
obfuscate matters on which the patient feels a need for resolution, or at least airing and acknowledgement.

Herein, lies a principal legitimation for the role of the consumer and the volunteer in palliative care.

COLLABORATION IN OTHER RURAL HEALTH CONTEXTS

Two other aspects of clinical service lend themselves to some involvement of consumers of health care: mental health services and rehabilitation. Here too, it is difficult to assess the impact of consumer involvement or to measure it.

However, the lack of mental health professionals in rural areas of Tasmania is leading to a pattern of sub-optimal “gap filling”. This “supply side” scenario contributes to mental health service provision being unevenly distributed, with the result that some areas are, by whatever agreed criteria, under-serviced. One risk of this “something is better than nothing” approach is that these “interim” responses become the accepted norm, and any unfilled vacancies eventually drop off the regional profile of health professionals, with concomitant reduction in ancillary services. So begins a regressive spiral that leaves certain communities permanently under-serviced. This pattern is evident in rural areas in every Australian state. Where previous efforts to recruit have been unsuccessful, the position is itself now at risk.

Communities that have survived on sub-optimal mental health, rehabilitation or other services, are eventually redefined as not needing, or able to do without, those services. In mental health, more than in most areas of health service provision, this can have a cumulative negative impact on a state’s profile of health service provision.

CONCLUSIONS

This paper addressed the potential benefits for health service delivery of consumer and volunteer involvement in the research process as it relates to rural health. Their successful involvement in rural health care delivery, research and planning can lead to research outcomes that are implemented in more meaningful and relevant ways for the benefit of people living in rural Australia.

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REFERENCES


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As Foundation Dean (from 1986) of the Faculty of Health Sciences at La Trobe University, Bendigo, he established a reputation for contributing to the health and higher education needs of rural Australians and for promoting interdisciplinary and intersectoral collaboration in health care. His commitment to advancing the health of rural Australians doubtless reflects his own origins as a kid from the bush. He grew up on sheep and cattle stations in the Riverina of NSW and the Flinders Ranges area of South Australia. Having, in the last 25 years, had a fat lamb farm in the Adelaide Hills and a deer farm and almond orchard in central Victoria, he likes the feel of dirt under his finger nails and the smell of sheep dip on his clothes — at shearing time anyway!

He has numerous policy and advisory roles and appointments for Australian States and the Commonwealth and currently serves on the Commonwealth Rural Health Support Education and Training (RHSET) Advisory Committee.