

Caring for people with a chronic illness: a place for the voluntary sector

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INTRODUCTION

In preparing this presentation, the dilemma of finding an appropriate title was presented. After procrastinating with my powerpoint presentation, hoping that powerpoint would magically illuminate the perfect title before my eyes, or at least inspire me, I came to realise the problem I was having was not a problem in itself, but a key finding in the research. My dilemma was in the use of the word “voluntary”. I know what I understand voluntary to mean but what understanding will the audience have of this word. Will they think of women in white aprons, selling lamingtons and scones, raising money for the local hospital? Or will they think of young executives from corporate organisations, providing accounting services, legal advice or sitting on a board of directors?

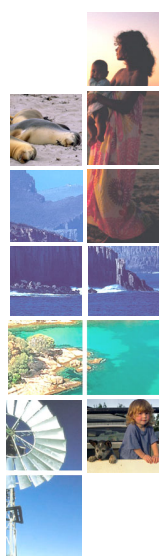
It became apparent that there were many characteristics to describe the work of these organisations and their work was very diverse. So with the aid of powerpoint, I came to the conclusion: Caring for people with a chronic illness: A place for the voluntary? non-government? not-for-profit? charitable? Third? sector. The abundance of terms used to describe organisations in this sector also highlights the transforming role of these organisations.

This paper is based on a sub-set of data collected from people with a chronic illness and their carers living in rural areas of Victoria. These people were members of support groups located in Moe, Traralgon, Bendigo and Horsham.

The overall aim of the research was to investigate the role of the voluntary sector in providing support for people with a chronic illness and their carers.

Specific research questions included:

- What is the experience of chronic illness?
- What are the health care needs of people with a chronic illness?
- What support do voluntary organisations offer to people with a chronic illness and their carers?



FOCUSING ON CHRONIC ILLNESS?

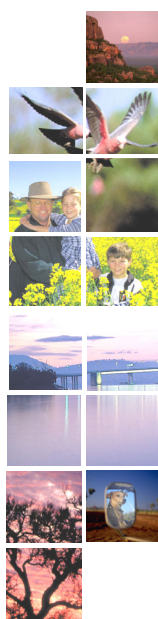
Rather than looking for definitions of chronic illness, there is a need to look at the experience of chronic illness. There appears to be similarities between chronic illness groups in addition to experiences which are specific to different chronic illnesses.

One reason to focus on chronic illness is that Australia, like other industrialised western countries, has experienced a significant shift in patterns of health and illness over the last 100 years (World Health Organization 1998; Australian Bureau of Statistics 1999). Since the 1920s there has been a significant decline in crude mortality rates, infant mortality rates, an increase in the mean age-standardised mortality for males and females and an increase in life expectancy (Abraham, d'Espaignet et al. 1995; Australian Institute of Health and Welfare 1998; Australian Bureau of Statistics 1999). Although mortality rates have decreased and life expectancy has increased, have these changes equated with decreases in morbidity in the population. Further examination of types of illness causing death and morbidity show a growing trend away from acute, infectious, communicable disease to long-term, non-communicable illness, disability and handicap (Murray and Lopez 1996; Australian Institute of Health and Welfare 1998; World Health Organization 1999). People are living longer, but living with greater morbidity.

With these emerging trends there is a need to look at responsive avenues for providing care to these people. At present, there are some limitations with the existing system of care for people with chronic illness. These problems include:

- Biomedical focus: a curative and mechanistic focus on the break down of body which can be fixed. Focused on identifying pathological causes, managing signs and symptoms and implementing treatment regimes.
- Acute care orientated, rather than continuity of care. Care also involves non-medical components such as social and welfare variables which can play a role in people's health. For example, health promotion, strategies for self-help and self-management to maintain health and lifestyle and develop positive experiences of health and well-being.
- Focus on institutional care as the main source of service delivery (ie. hospital wards, outpatients, doctor's rooms). Yet a major part of their health care occurs outside the formal health system usually in their own homes. People's self management and the roles of the family and carers are an integral part of people's health care.
- Who is the expert of the illness, the health professional or the person with the chronic illness?

Caring for people with a chronic illness needs to include the physical, mental, social, cultural and economic elements of illness. There is a need to look at responsive avenues in addressing the need for *care* and *support* for people with a chronic illness, attention turns to the voluntary sector.



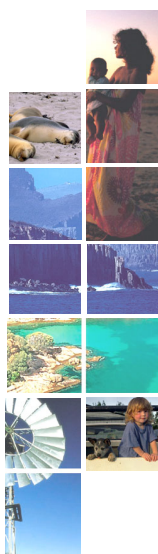
VOLUNTARY ORGANISATIONS IN AUSTRALIA

In Australia, voluntary organisations have played an interactive role in the public system since the early colonial days. The first voluntary organisation emerged in 1813 and is now known as The Benevolent Society of NSW (Dickey 1987). The number of voluntary organisations began to grow in the latter half of 19th C (Australian Council of Social Services 1994; Lyons 2000). Lyons (2000) reports, “the non-profit sector played a larger role than government in the actual delivery of health, income support and community services combined” (p,174). Following Federation in 1901, government began to take on a more active role in social welfare. Health became the responsibility of government and the medical profession and issues such as poverty and unemployment were addressed by voluntary organisations (Dickey 1987; Community Services Victoria 1992).

Although financial welfare assistance from government became more accessible after World War II, this period also saw a growth in the number of non-government organisations which were established. From the 1960s onwards, approximately 70 to 80% of non-government organisations were established (Milligan, Hardwick et al. 1984; Community Services Victoria 1992). Voluntary organisations were also developing new roles, the focus of the sector had moved to people with disabilities, particularly physical handicap and people with multiple disabilities. Policies of deinstitutionalisation, community integration and care, and an emphasis on prevention saw a larger role for voluntary organisations (Community Services Victoria 1992). However, as social and economic climates have changed, so to have the areas of service provision for voluntary organisations. There has been a move away from religious groups caring for people in poverty and the destitute to organisations run by professionals providing services for illness-specific conditions. There is an abundance of literature which discusses the social, political and economic roles of voluntary organisations. It should be noted that most organisations act simultaneously in these roles and the economic role should not overshadow their influential role in social and political activities (Lyons 2000; Ristevski 2001).

Yet, it has also been questioned about the appropriateness of voluntary organisations in the delivery of direct care (Crombie and Coid 2000). It has been argued that voluntary organisations are beneficial in providing social support and welfare services, but when it comes to delivering interventionist services, there needs to be more evidence to evaluate their effectiveness. It is also questioned to what extent voluntary organisations should be involved in planning and implementing policy. It is recognised that the participation of these organisations is important in representing the needs and views of their consumers, however, there is a question as to the extent they should influence policy without a clear evidence base of their effectiveness.

In this paper I will focus on the experience of chronic illness, access to health care services for people with chronic illness and what voluntary organisations have provided for people with a chronic illness in rural areas. The paper will concluded with a discussion of some of the pressures these organisations face which might impact on their roles and provision of care and services.



METHODS: QUALITATIVE CASE STUDY

Semi-structured interview and focus groups were conducted with 24 people with a chronic illness and 9 carers from a rural area. This constituted nearly 30% of the sample (N=119). Of these people, 24 were females and 8 were males. The chronic illness groups which were examined included: arthritis, epilepsy, multiple sclerosis (MS) and renal failure.

The voluntary organisations which participated in this study reflected the four chronic illness groups: arthritis, epilepsy, MS and renal failure. These organisations had their Head office in Melbourne and regional offices or workers in Victoria. Semi-structured interviews were conducted with 44 people working in voluntary organisations. Documentary sources such as newsletters, archives, pamphlets, and annual reports were also examined. See table 1 for an overview of the voluntary organisations in this research.

Table 1 Characteristics of voluntary organisations in the study

	Organisations			
	A	B	C	D
Illness group	Arthritis	Epilepsy	Multiple Sclerosis	Renal failure
Year of establishment	1964	1964	1956	1972
Founder	Health professional	Carer	People with MS	People with renal failure
Paid staff	50–100	<50	250–300	0
Volunteers*	200–300	<50	1200–1300	<25
Consumer Membership	6000–6500	<1000	3000–3500	<1000
Regional Office/s**	Community partnerships (no office)	Ballarat, Bendigo, Geelong, Moe	Camberwell, Footscray, Geelong, Frankston	None
Total Annual Income	\$2.5–3 million	\$1–1.5 million	\$9.5–10 million	\$50–60, thousand
Government funding	\$2.5–3 thousand	\$6–6.5 thousand	\$6.5–7 million	0

*Does not include members of the general committee/board or patrons

** All the organisations' head offices were located in Melbourne

FINDINGS

Personal experiences of chronic illness

The personal experience of chronic illness did not differ in the rural setting. Thematic analysis of the data reveals the experience of living with a chronic illness is not only the physical manifestation of the illness, but also encompasses a diverse range of social and personal components. Themes which emerged included:

- emotional responses – denial, vulnerability, loss, relief, legitimation, and control
- decisions, strategies and actions – making and resisting changes

- social images and perceptions of illness – invisible and unpredictable, stereotypes of illness, practical and symbolic meanings of aids and appliances, perceived severity of illness
- family and friends – disruption of social roles, impact on relationships
- work and school – interactions with colleagues and school friends, participating in and contributing to society (Ristevski 2001).

Living in a rural area

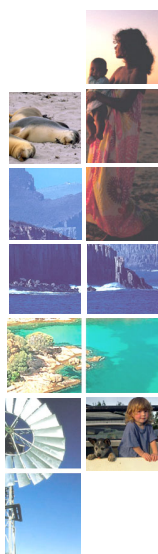
The difference which emerged the urban and rural data showed that for people living in rural areas the *provision of adequate health care services* was not always available or accessible (This is no surprise). People raised structural issues, rather than clinical/medical issues related to care. These included

- access to specialist – for example, rheumatologists, neurologists
- access to appropriate health care providers – for example, GPs who knew about their chronic illness
- cut backs in funding to services which meant services were less accessible due to cut backs in the hours of operation, longer waiting lists, reduced ongoing care due to waiting lists and moving people through the system, and a feeling of uncertainty in accessing care
- transport and distance to drive to health services in the rural and metropolitan areas. Issues of mobility were raised for people with chronic illness, especially when a carer, or someone else if they did not have a carer, needed to take the person to their medical appointments
- communication between health professionals in urban and metro areas. For example, the specialist in the city did not usually communicate with the person's local GP. Also communication between specialists (wherever they were located) was poor.

Other spin offs included:

- a great financial impact – all these activities required money to undertake them, or if time had to be taken off work, then money is lost, especially if a carer needs to come along with the person
- metro hospitals were impersonal and lonely, people got homesick (Especially for people with renal failure who needed to be in hospital for a long period of time). It was also difficult for peoples' families to visit and provide support.

People stated that the provision of health care not only needed to provide effective clinical care but to also consider the wider social and personal factors associated with chronic illness. (Ristevski 2001)



The role of voluntary organisations

Analysis of the data showed that the provision of ongoing support and services is an area where voluntary organisations have been innovative in the health care system, particularly, for people with a chronic illness. Voluntary organisations provided services, which focused on the individual, social, economic and clinical needs of people. Services delivered by organisations in the public sector were largely targeted toward acute care, were less flexible, and increasingly concerned with cost efficiency.

In this study, voluntary organisations were found to provide the following support services for people with chronic illness and their carers in a rural area.

The provision, access, availability and communication of **information**. This was an area which was not adequately addressed in people's health care experiences. It was not that the information wasn't there, but it was not either passed on, or accessible. Information that was provided included:

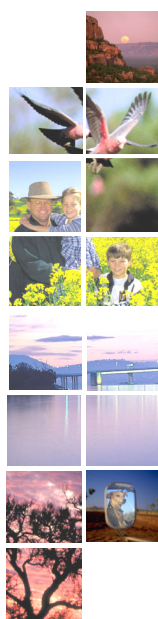
- a diversity of information – verbal, print or electronic form
- clarification of medical information
- self-management strategies (which was not readily available from the public system)
- referrals to other services – for example, health professionals such as specialists, allied health or complementary medicine. Accessing aids and appliances and availability of council services
- people could choose as much or as little information as they wanted and could access information which was appropriate to their stage of chronic illness or level of interest.

Education and advocacy activities

- Organisations encouraged and facilitated reciprocal learning about people's needs between health professionals and people with chronic illness.
- Organisations helped to educate the community about chronic illness and reducing stigma attached to illness (eg. arthritis can affect young people), clarifying stereotypes (eg. People with MS are not drunk), and what to do in an emergency (eg. Clonic tonic seizures and epilepsy – first aid and when to call an ambulance).
- In addition to educating community groups about chronic illness these activities also played an advocacy function.

Social support (particularly through support groups and social events)

- Enable exchange of practical and technical information through experiential knowledge in a social setting. Learning from others situations and experiences.
- Provided companionship, friendship, caring, happy and fun.
- Reduced isolation and took people's focus off their illness for a period of time.



- Non-stigmatising environment, comfortable, understanding from other people, no need to explain, didn't feel as if they were whingeing.
- Encouraged people to be more proactive in managing their illness, become more motivated, develop greater self-esteem, positive encouragement.
- Practical help (cooking dinner for someone who was acutely sick)
- Caring (cup of tea friend)

This quote summaries the role that social support played for these people:

Because it's nice to have someone that understands it, or somebody that talks to you and you're not sort of made to feel different or whatever else. That's half the battle isn't it? I mean, I can understand it more because I listen and I listen to all the others. We're either supporters, we either support carers or we're either the actual patient. Not patients, but, person with epilepsy (Helen).

Issues for voluntary organisations in rural areas

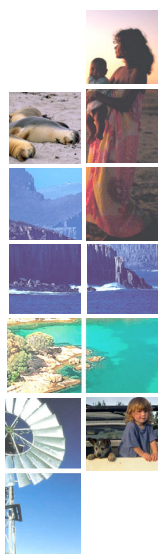
People highly appreciated and valued the services the organisations provided but would have liked the organisations to have more contact in the rural areas and diversify their services into the rural areas. Most of the organisations' services were based in the metropolitan areas, which made it difficult for people from rural areas to access. Issues such as ability to attend due to access, time, travel, distance, energy and practicality, not necessarily through lack of interest or motivation. It was felt that organisations needed to bring more of their services to the rural areas. For example, providing more information session, educational programs and courses.

It was recommended that organisations establish offices in regionalised centres with rural workers. This would allow greater access to the organisation's services and a worker in a local area would be better equipped to understand the local needs within the context of the rural environment. Yet, in some cases where a country worker was available, this position was usually filled by one person who provided information, support, education and advocacy to a whole region (eg. 1 worker to cover Gippsland). In some cases, this person worked on a fractional basis and became overloaded with work.

On an ad hoc basis, people with a chronic illness and carers also participated in some of the organisation's activities, particularly fundraising, promoting information, community education, publicity of the organisation, running support groups, acting as a contact person for newly diagnosed. These people worked in a voluntary capacity without the formal recognition of a volunteer. The problem that this scenario poses is that this group of people while trying to "fill the gap" of service availability might mask the inadequacies in the system of care ("at least somebody is doing something") and not receive formal recognition of their communities needs.

People also recommended that organisations also needed to provide information and promote local support groups and contact people.

Some people also questioned the priorities of the organisations in metropolitan areas. It was suggested by one focus group that rather than paying an expert to develop a



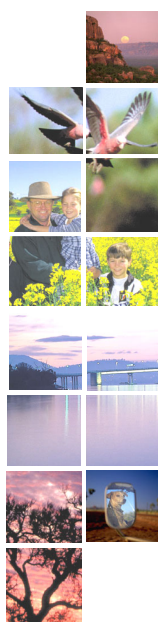
telephone phone link system, money also needed to be spent on developing services in regional areas.

CONCLUSION

Other issues which voluntary organisations were increasingly experiencing is the increase in abundance of organisations (voluntary, private or public) competing for consumers. These pressures have led to expanding priorities in the areas of promotion, marketing and fundraising activities. Organisations acknowledged that with the limited resources in the community, especially funding from government and competition in fundraising, strategies had to be developed to maintain the viability of the organisation. This was not a new role, but more pervasive and important. Organisations increased the size and role of these activities and in some cases, formally established positions and departments to undertake these activities. Promotion and marketing activities included marketing the image of the illness and the image of the organisation. Fundraising strategies were more proactive, and innovative. People were enticed with incentives and benefits, services were sold, specialised events were conducted, corporate investments and community networks were actively sourced, and there was a shift to employing professional fundraisers (Ristevski, Tacticos et al.).

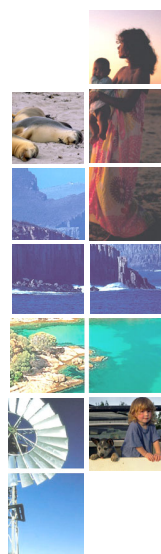
The organisations' activities were becoming orientated around first, income generation, then education, information and advocacy. However, does this expanding area compete with the organisations altruistic motives? This raises the question: Altruism or entrepreneurialism? (Ristevski, Tacticos et al.). Will these organisations "lose the vision"? (Wearing 1994; Salamon 1995; Ellingsen 2000, 17th June). What will be the implications for consumers, in this case, people with chronic illness and their families? How will voluntary organisations in rural areas sustain themselves? Volunteering activity in rural areas is more at risk due to more women entering the paid workforce, an increasingly ageing population, young people moving to cities where there are greater employment and career opportunities, and with an abundance of organisations promoting their cause there are limited fundraising opportunities.

Finally, there is the question of competition or collaboration between organisations. There were competing ideas within the organisations on the appropriate manner in promoting the "cause". Organisations needed to be sensitive and mindful of ethical issues in promoting the chronic illness, but also recognised the need to be proactive rather than reactive in promoting the illness and the organisation. There was competition for public recognition of the "cause" and the organisation's activities as the advocate or representative group for the people with a chronic illness. Although people in organisations spoke about the need for collaboration between organisations, the practice was "you-tell-me-your-secret-first-and-then-I'll-half-tell-you-mine".



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PRESENTER

Eli Ristevski is a lecturer at the School of Rural Health, Monash University. She has been conducting research into the role of voluntary organisations in Victoria's health care system. She has worked with a number of consumer organisations and support groups in the area of chronic illness to develop a profile of the work of voluntary organisations. She has also taught in a range of postgraduate and undergraduate subjects that include the sociology of health and illness, disability, research methodology, the principles of public health and rural health issues and practice.

