

Community care for people with epilepsy in a modern society: The New Zealand model

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Abstract

The Epilepsy New Zealand Field Officer scheme is a model for the provision of community care for people with epilepsy. Epilepsy New Zealand is a voluntary organization. It runs the community care service by employing 27 Field Officers throughout the country. The Officers provide support and information to people with epilepsy, their family and the general public. It is estimated that the service covers about 10% of epilepsy patients in New Zealand. All Field Officers are required to study for nationally recognized Certificate and Diploma in Epilepsy Care qualifications. The funding for this service is by a grant from the Government, charitable trusts and other fund-raising activities.

INTRODUCTION

The ultimate goal for all work with people with epilepsy (PwE) is to improve quality of life for them and their families. Essential to doing so is good medical care, but other types of care must also be provided. The reason is that 80% of PwE live in their own homes with their families, and so need care in the community as well as in the clinic. This paper describes one system of community care, which, although it has been developed in New Zealand, could be used in other contemporary societies.¹

The occupation of an epilepsy-focused community worker has different titles in different countries, ranging through nurse, social worker or educator to field officer. In this paper I have referred to them as a “Community Care Worker” (CCW)

THE NEED

The CCW can fulfil several functions: (1) Educate the public about the nature and treatment of epilepsy; (2) Educate the PwE and their family about epilepsy and its treatment; (3) Provide emotional support to help deal with trauma and stigma; (4) Train the family of the PwE to observe and report seizure symptoms; (5) Reinforce the clinician’s instructions and encourage adherence to a antiepileptic drug regimen; and (6) Educate the PwE and their family in antiepileptic drug use.

Further functions the CCW can fulfil include: (7) Provide information on local clinicians specialising in epilepsy; (8) Inform the PwE about available societal benefits, subsidies and other services; (9) Facilitate the establishment

of self-help groups for emotional support; (10) Advocate on behalf of the PwE to authorities, clinicians, family and community; (11) Provide care in the home, especially if the PwE cannot drive; (12) Instruct teachers, employers, social workers, officials, and others about epilepsy; and (13) Educate the community about dealing with epilepsy, AEDs, and first aid.

THE COUNTRY

New Zealand has a population of 4.2 million, scattered over 250,000 km², of whom 70% live in 17 large towns and cities.² The GDP in 2006 was USD 25,200 per person (as compared to USD 12,100 for Malaysia and USD 28,100 for Singapore).³ There are hospitals throughout the country, but only one epilepsy clinic and no residential epilepsy centres. Thus there are many PwE living and working in the community.

SERVICE PROVISION

Epilepsy New Zealand is a voluntary organisation, financed by grants won from the government, charitable trusts and agencies, together with a variety of fund-raising activities. Its 17 branches employ 27 CCWs, known as “Field Officers”. Each of these carries an active caseload of approximately 100 and a passive caseload of approximately 300.

Their clients are self-referred, and learn about the CCW service through advertisements, advice from the doctor, or word-of-mouth. In addition Epilepsy New Zealand maintains an 0800 line which automatically connects the caller to their nearest branch and its CCW. Contact is also

listed in the Yellow Pages throughout the country. Contact is therefore usually initially by telephone, but later may include home visits.⁴

An important aspect of the CCW's work is public education. They work with self-help groups of PwE and their parents and families. However they also give talks about epilepsy to schools, trainee nurses, teachers, ambulance officers, and others. Other target audiences include employer organisations, company employees and trade unions. They also frequently mount displays and staff booths at shows, expositions and displays. They provide interviews and articles for newspapers, magazines, radio and TV, and give talks to service clubs and community groups.

STAFF SELECTION AND TRAINING

When a CCW position falls vacant, application to fill it is invited through advertisements in the local media. Applicants are short-listed and interviewed by a panel comprising of both national and local personnel.

Most applicants have previously been trained as nurses, teachers or social workers. Epilepsy-specific training commences with two days of induction training by National Support Centre staff. They are then required to study part-time for a Certificate, followed by a Diploma in Epilepsy Care. In addition all CCWs are expected to attend an annual three-day live-in seminar prior to the Epilepsy New Zealand annual conference. They are also encouraged to attend relevant conferences, workshops and seminars, and receive a regular newsletter from the National Support Centre on the latest epilepsy care developments.

STAFF QUALIFICATIONS

Once appointed, the CCW commences part-time study for a qualification in community epilepsy care which has been approved by the New Zealand National Qualifications Authority.⁵ This qualification has two stages and requires at least two years of correspondence study. It is required of all epilepsy CCWs and has been designed and is taught and assessed by senior CCWs with Epilepsy New Zealand. Its curriculum has been approved and is monitored by neurologists and paediatricians specialising in epilepsy care.

The National Certificate in Epilepsy Care develops in the CCW the skills and knowledge necessary to establish and maintain working relationships with people who use the services of Epilepsy New Zealand, as well as with schools and other health, welfare, social and community

organisations and groups. The National Diploma in Epilepsy Care instructs the CCW how to conduct significant interaction with people who have needs for a range of support services for epilepsy and epilepsy-related difficulties. Having completed it, the CCW is able to design coping strategies based on both pharmacological and non-pharmacological management, in accordance with historical and multicultural beliefs. It also ensures that they have the anatomical and physiological knowledge necessary to record and describe client medical history

STAFF EMPLOYMENT

Once employed, the CCW is managerially supervised by National Support Centre staff. They are also expected to arrange for professional supervision, often with a senior social worker or psychologist. Day-to-day supervision is by their local Branch of Epilepsy New Zealand. A nationwide pay schedule and conditions of employment are negotiated annually. Many take up voluntary membership of the Public Service Union.

FUNDING

Epilepsy New Zealand has a contract with the New Zealand Ministry of Health to provide service throughout the country, which provides less than half of the cost of the CCW service. Further funding for salaries, facilities and equipment is raised by competitive grants from government agencies, such as the National Lotteries Board; grants from corporations such as drug companies and charitable trusts, and fund-raising activities such as raffles, appeals, sales, sponsorship, and events.

STAFF FACILITIES AND EQUIPMENT

To provide both support and educational services, each CCW requires an office and computer, together with a telephone, answering machine, email, and fax. Each is also provided with a car, often sponsored by a local dealer, as well as funding for petrol and maintenance. Other essential equipment includes a data projector, screen and a video/DVD player. They are also supplied with leaflets, books, and fact sheets by the National Service Centre.

COVERAGE

Many Epilepsy New Zealand CCWs work part-time, so 27 employees is the equivalent of

approximately 21 full-time employees, which gives a ratio of approximately 1/200,000 for New Zealand's 4.2 million population. An unpublished study has shown New Zealand's prevalence rate for epilepsy to be approximately 0.6%, similar to that of many developed countries, meaning that there are some 25,000 new Zealanders with active epilepsy at any one time. The case loads mentioned above mean that approximately 2,100 of them, or less than 10%, are being served by an Epilepsy New Zealand CCW at any one time. Assuming a need rate of 15%, an ideal ratio would be 1/100,000 population, or 42 CCWs. Moreover the coverage is uneven, with fewer in Auckland, New Zealand's largest city. Epilepsy New Zealand is working to increase the numbers of CCW and ensure a more even coverage of the service.

- Care For People With Epilepsy. Current Problems in Epilepsy, No 16. London: John Libbey, 2001:35-40.
2. Statistics New Zealand Website at <http://www.stats.govt.nz/default.htm>
3. CIA World Factbook at <http://www.cia.gov/cia/publications/factbook/index.html>
4. Epilepsy New Zealand website at <http://www.epilepsy.org.nz>
5. New Zealand Qualifications Authority website at <http://www.nzqa.govt.nz/nz/index.html>

PROFESSIONAL RELATIONSHIPS

Ideally, the General Practitioner, the epilepsy specialist and the CCW should work as a team, as each has a unique role to play. Therefore it is important that the CCW establishes a good working relationship with local General Practitioners and specialists. It is also important that the clinician should refer patients on to the local CCW to provide services, education and support, which the clinician does not have time to provide. Moreover the CCW should be able to refer a client back to the appropriate clinician when the need arises.

CONCLUSION

Epilepsy care is incomplete without community care. Community care is a profession, requiring both initial training and constant refresher training. The CCW needs to be seen as an integral part of the team provided by society for the care of people with epilepsy and their families. Consequently, every society needs to recruit, train and fund CCWs to care for people with epilepsy. New Zealand is one of several countries which do so. I recommend the Epilepsy New Zealand Field Officer scheme as a model for the provision of community care for PwE in other countries. By doing so, we work toward improving the quality of life for people with epilepsy and those who care for them

REFERENCES

1. Hills MD. Providing community care for people with epilepsy and their families. In: Pfafflin M, Fraser RT, Thorbecke R, Specht U, Wolf P, eds: Comprehensive