

Recognising the changing boundaries of illness in defining terms of chronic illness: a prelude to understanding the changing needs of people with chronic illness.

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Abstract

Definitions of chronic illness do not reflect the changing nature of chronic illnesses. When definitions in the literature, which guide and inform thinking in a field, remain static they are in danger of creating stereotypes. This can have an adverse influence on the care of people with chronic illness. Debates over the use of terms associated with chronic illness will lead to a better understanding of the place of chronic illness in the world of health and illness and ultimately lead to services that better meet the needs of consumers.

Introduction

Chronic illness or chronic disease is not a static concept (Davis and Groves, 1999; Davis and Groves, 2000). This is acknowledged by the World Health Organisation in tracing the relationship between the ageing population and increased prevalence of chronic illness as a worldwide problem. In addition, new illnesses emerge while others may become less formidable in their impact on the individual and on health systems (Porter, 1997). Data published in Australia's Health 1998 provide us with ample evidence that illness may move from the boundaries of terminal to those of chronic over time. For example, the South Australian Cancer Registry provides some clear examples since it regularly publishes survival rates (AIHW, 1998). It has recorded significant improvements in survival rates for some cancers. The survival rate of cancer of the cervix has improved from 68% between 1977 and 1985 to 74% between 1986 and 1994. The survival rate in prostate cancer has improved from 61% between 1977 and 1985 to 68% between 1986 and 1994. Cancer of the oesophagus has shown an improved survival rate from 9% to 16% for the same periods. The improved survival rates for gynaecological cancers, cancer of the testes and Hodgkin's Disease are said to be due to improved treatments, over the past ten years (AIHW 1998). These figures suggest that some cancers are now more likely to be in the category of long term or chronic illnesses, rather than terminal illnesses.

Even within the boundaries of chronic, the picture can still change. Both diabetes and asthma impact on the health of the Australian community. The incidence of diabetes is increasing. The 1995 National Health Survey reported a 26% increase since the 1988-90 survey, with 23.8 per 1000 people reporting diabetes mellitus at some time in their lives (AIHW, 1998). The increase is partly due to the ageing of the population. While

asthma is becoming more prevalent among young adults and in the 1995 National Health Survey 11.3% of Australians reported asthma as a recent or long-term condition, the number of deaths from asthma is declining. Between 1988 and 1996 the number of deaths from asthma fell by half for those aged between 5 and 34 years of age (AIHW, 1998).

Asthma, diabetes and cancer are three of the national priority areas, which demonstrate the benefits of improved treatments and attention to risk factors. However, there are changes taking place in other illnesses. In the 1980s HIV was considered tantamount to a death sentence. Services concentrated on palliative care. People with HIV structured their personal lives in terms of a shortened life span; leaving employment, taking superannuation payouts, and prioritising their activities. The advent of antivirals has improved survival rates (Ezzy et al, 1998). Some people with HIV are now considering a return to work, or retraining while others are facing prolonged periods of relative poverty (Ezzy et al, 1998; HIV Futures Study 1999).

The introduction of prophylactic Factor VIII therapy has produced amazing results for some children with haemophilia (Haemophilia Foundation of Australia, 1994). Prophylactic treatment reduces the number of bleeds they experience, as well as reducing the complications from joint damage that accrue over time. This in turn reduces the need for treatments for joint inflammation, including both medications and orthopaedic surgery. The extent to which there is now a gap between the older generations that suffered considerable disability and the young generation where most are symptom-free, indicates that the face of the disease itself has changed. A similar change in the epidemiology of Ross River virus has also been observed (Selden and Cameron, 1996).

There are about 135,000 people with epilepsy in Victoria (Epilepsy Foundation of Victoria, 1999). In the United States there is an estimated 2.3 million people with epilepsy, 25% of whom have intractable seizures. Data from the American Epilepsy Foundation (1999) indicate that the incidence of epilepsy is on the increase due to its association with problems of ageing, including stroke, acquired brain injury, Alzheimer's disease and brain tumours. While overall the outlook in terms of effective control is improving, a new phenomenon has been observed in both the United States and in Australia. This is sudden unexplained death in epilepsy (SUDEP). Young people between the ages of 20 and 40 with epilepsy are now more likely to die suddenly and without explanation. At the same time, other young people are now more likely to die of the seizure itself, while others suffer brain damage (EFA, 1999).

The above observations can be seen in the context of increasing life expectancy. There have been recent reductions in death rates at older ages, especially for diseases of the circulatory system. This has led to increased life expectancy. It suggests that within the overall population some people are living longer but living "sicker". Support for this view is found in the National Health Survey in 1995 where 73% of males and 76% of females reported a long term condition, including sight problems, hearing problems, hypertension, arthritis, asthma, hayfever and sinusitis.

A complex picture begins to emerge. Within the broad picture of people living longer but "sicker" there are also people such as those with haemophilia, some cancers, cystic fibrosis and HIV who are sick people with better prognoses than in the past. The example of sudden unexplained death in epilepsy indicates that there are also people dying in a manner not previously recorded.

The complexity suggests that the boundaries of chronic illness are not only changing due to improved treatments and health promoting measures to address risk factors but that we are beginning to recognise these boundaries are of a fluid nature anyway. Tuberculosis is a disease that over the last three centuries has moved between the boundaries of terminal, incurable and chronic. This relationship has depended more on environmental factors than treatments (Porter 1997).

If people are living longer, and sometimes living longer with illnesses that were once terminal, it becomes very important to understand the attributes of chronic illness and to define it in a manner that reflects that boundaries change. This is an important exercise because definitions guide and inform current thinking in a field. Through the meanings they convey, they influence and guide the way in which a person is treated and influence the attitudes that are held by both practitioners and lay people about particular diagnoses. When definitions are not questioned and revised they become stereotypes (Gilman, 1988), no longer reflecting the relationship between medicine and illness but adversely influencing attitudes held about this relationship.

In 1994, Clarke made a similar point. “The labels chronic and acute are value-laden. They are shaped by and in their turn further shape, the attitudes not only of policymakers but also of doctors and other health carers. Thus chronic in vernacular medical terminology can become shorthand for unexciting, acute for exciting.”

A recent review of the way the terms “chronic”, “chronic illness” or “chronic disease” are used in current literature suggests that the fluid nature of the boundaries between illnesses has not been captured (Walker 1999). Instead, the way in which chronic illness (or disease) is conceptualised in current literature constrains such a development. Current definitions are more likely to reflect the internalised attitudes of policymakers and health professionals, than the changes taking place.

A moral dimension is evident in much literature concerning chronic illness. Sontag (1989) observed that when the relationship between behaviour and cancer was drawn, there were also parallels drawn about indulging in risky behaviours. If people with chronic illness appear to have caused their illness or if they fail to comply with treatments, they are regarded as abusing a trust placed in them on behalf of their body (Lupton, 1994). The term “sick” conveys a negative and stigmatic quality, so to remain sick suggests irresponsibility as well (Comaroff, 1982; Lupton, 1994; Millen and Walker, 2000).

Examples of current usage of the term “chronic”

In Australia’s Health 1998 the term chronic is defined as persisting over a long period (AIHW 1998). Duration alone is a common indicator of chronicity. It is the definition used for indicators in the 1992 study “Enough to Make You Sick” (NHS 1992). A definition on this basis, provided the time frame is short enough, allows for the inclusion of seasonal illnesses such as influenza, hayfever, the common cold as well as more severe illnesses such as diabetes, heart conditions and cancers. Duration as an indicator of chronic illness may sometimes be refined as the length of time a person has off employment or studies due to their incapacity. Thus, anyone whose illness incapacitates them for more than six weeks in a year may be arbitrarily considered to have a chronic illness, using these unsophisticated indicators.

The insidious and ultimately incurable nature of an illness may mark it out as chronic. Clarke (1994) gives the example of chronic heart failure which may “begin insidiously and progress gradually into a chronic state”. A common term associated with epilepsy that remains uncontrolled by medication and hence, incurable, is “chronic, intractable epilepsy” (Camfield and Camfield, 1996). Other articles may emphasise the periodic, episodic or recurrent nature of an illness as distinguishing features of chronicity (Clarke, 1994). Examples of this occur in literature concerning arthritis and asthma (Hauptmann, 1994). Persistence of asthma may be seen in other articles as the central identifying feature of asthma (Altraja and Laitinen et al, 1996). In “Help Where Help Is Needed: Continuity of care for people with chronic mental illness” (1993) the critical dimensions of chronic mental illness are duration, disability and diagnosis.

The extent to which any one of these attributes of chronic illness is marked as a definitive indicator of chronic illness depends on the professional perspective of the writer. Generally, articles referring to chronic illness fall within one of three broad perspectives or models. The first is the biomedical model, which seeks to explain ill-health in terms of internal malfunction of the body and may reduce all explanations of chronic illness to biological and pathological factors (Knight, 1998; Buttfeld and Buttfeld 1990; Furnham and Bower 1992).

A second model is the biopsychosocial model that attempts to account for, and include biomedical, behavioural and social factors. Finally, there is a category commonly referred to as the behavioural one, in which chronic illness is distinguished in terms of people’s behaviours.

The biomedical model

Biological markers provide a means to distinguish between acute and chronic phases of an illness. Chronic renal failure is distinguished by uraemia, while diarrhoea becomes chronic when more than 200g of stool per day is passed for more than three weeks. A neurooncology article on low-grade gliomas defined chronic epilepsy as a history of preoperative seizures with a median of 14 years (Bartolomei et al 1997).

In the absence of biological or pathological markers, biomedical literature adopts social indicators, such as length of time off paid employment, lack of response to treatment or non-compliance on the part of the consumer. This is essentially a behavioural model (German, 1988; Guimon, 1995; Reeves et al, 1997).

Explicit definitions of chronic are rare in biomedical literature. Articles on asthma and diabetes describe them as chronic without developing the implications of this term (Abramson et al 1995; Harrison 1998). Chronic may be a synonym for persistent, unexplained, of indeterminate diagnosis or relapsing (Hickie et al 1995; Bunce et al 1994; MacLellan, 1994). These variations suggest that there is little agreement as to what constitutes a chronic disease or which diseases are defined as chronic within the biomedical model.

The biopsychosocial model

Other health disciplines are likely to employ the biopsychosocial model. Within this model, there is also a wide divergence of opinion as to what constitutes chronic. Nursing literature takes a qualitative approach, based on health outcomes. Place, an academic nurse (1993) argues for a qualitative approach that includes people's experiences of the hardships imposed by their illnesses, including financial constraints, changes to their social relationships, employment prospects and the need for attention to their bodies. Another nursing article draws on qualitative research to argue for improved relationships between people with chronic illness and health professionals because they will continue for extended periods of time. Emphasis on the social outcomes is seen in another article on nursing in epilepsy which argues that a strictly clinical approach with no attention to psychosocial issues means people with epilepsy are denied participation in routine lives (Long and Reeves, 1997).

Policy literature, working within this model, is more likely to attempt explicit definition of chronic illness. *Enough To Make You Sick: how income and environment affect health* (1992) is an example of the biopsychosocial model where chronic illness is related to high risk behaviours of people in lower socio-economic groups. In this study chronic illnesses were listed as back trouble, hayfever, arthritis, hypertension, asthma, migraine, deafness, eczema and dermatitis, varicose veins, high cholesterol, bronchitis and ulcer. This list emphasises the association between chronic illness and poor behaviour including non-compliance. Similarly, the National Health Strategy's 1993 paper on chronic mental illness is within this biopsychosocial model, which uses a tripartite model of diagnosis, disability and duration as its critical dimensions. Schizophrenia, anxiety disorders are amongst those with persistent and long-term symptoms. Disability refers to the extent to which a person's ability to function within society is affected. This also includes an appreciation of the social response to the person's illness-related behaviour. Duration in this context is not simply length of time an illness persists but includes the length of time a person requires hospitalisation and treatment from specialist services. Duration in this context becomes a prognostic indicator. A discussion of the fluctuating and episodic nature of chronic mental illness is also included.

Policies in which the ageing of the Australian population and chronic illness are associated emphasise the cost of chronic illness to the Australian economy. In 1990, the Victorian government recognised the needs of the growing number of elderly in the Victorian community. This policy argued that illness was not an inevitable part of old age but many of the chronic illnesses associated with it, could result in disabling conditions. Examples were arthritis, foot problems, cardiovascular disease, osteoporosis, dementia, hearing and sight problems. Strategies to reduce chronic illness resulting in disability or handicaps included health promotion and health maintenance activities, including self-management. This approach suggests an underlying behaviourist model. The more recent Chronic Disease Self Management Policy of the Department of Health and Aged Care (1999) has many features in common with this model.

Many policies concerned with ageing and chronic illness emphasise the costs involved. Victoria's "Health to 2050: developing Melbourne's hospital network" (1995) argues for the scaling down of hospital care for elderly people with chronic conditions with a corresponding increase in continuing care in their own home. The services to be provided by this means were rheumatology, renal dialysis, rehabilitation, palliative care, and oncology services. In emphasising the costs of elderly people with chronic illness, there are strong associations made that ageing inevitably produces costly dependence.

The behavioural model

This model has far less application in literature concerning chronic illness at present. It is more extreme as it leaves out socio-economic factors. Better Health Outcomes for Australians (1994) is an example of this model in which chronic illness is associated with preventable diseases.

Discussion

It is worth considering the impact of conceptual models of chronic illness on the services and service delivery to people with chronic illness.

Furnham and Bower (1992) argue that models explain the aetiology of mental illnesses. Different models influence the treatment of people with schizophrenia as well as the attitudes that health professionals hold about their clients. For instance under a medical model a person with schizophrenia faces objectification, physically intrusive treatment, and may be stereotyped as non-compliant. The social model of schizophrenia portrays people with schizophrenia as the victims of modern society. The psychosocial model, the authors argue, offers people with schizophrenia psychotherapeutic interventions and an appreciation of social factors in putting them at risk in the first place.

A similar observation applies to the broader range of chronic illnesses (Buttfield and Buttfield 1990). Much of the use of the terms chronic disease and chronic illness in both clinical and policy literature imply an underlying stereotyping of the experience of living with a chronic illness.

Consider the following definition of chronic illness by the Commission on Chronic Disease, 1956 quoted in Strauss (1975). "All impairments or deviations from the normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alterations, require special training of the patient for rehabilitation, may be expected to last, to require a long period of supervision, observation or care".

In this case, chronic illness is defined in language that serves to stigmatise and marginalise those who experience it. To have a chronic illness is to be impaired, to have deviant health. There is an underlying assumption that there is a "normal" state where no impairments exist. Those who deviate from this state will incur costs of rehabilitation and long term care. The language is itself passive, suggesting that the importance of chronic illness is its outcomes on "normals". Experience of chronic illness has thus been objectified into outcomes. Furthermore, "non-reversible pathological alterations" ignores the contribution of medical interventions, for example recent treatments available in cystic fibrosis. The phrase also ignores the experience of illness not necessarily measured in terms of pathological alteration, but nonetheless real for the sufferer, such as chronic fatigue syndrome, personality disorder and chronic pain.

Definitions of people as belonging to a marginal and deviant state in terms of the amount of time they have off work, or the amount they cost to the economy or their degree of dependency are not objective research indicators. Rather, they are the assumptions underlying value judgements.

Often when the words from clinical articles and policy documents are translated into everyday language, a picture emerges of people with chronic illnesses as dependent, passive recipients of treatment, who are expensive to treat, who may have a high rate of non-compliance and contribute little to society.

It is interesting to examine each of these stereotypes in turn as they appear in the literature. Closer examination often reveals that there is no pragmatic basis for an assertion, or that the reality is far more complex.

Dependence: This view of people with chronic illness in policy documents, associates it with old age. The argument goes something like: when people get old, they succumb to expensive long-term illnesses, which places greater burdens on the health and welfare systems. The strong association between ageing and chronic illness reinforces the view that elderly people are dependent. In fact, the situation with elderly Australians is far more complex. There are many healthy elderly people in our communities, who are active, who provide services such as childcare to their families and who care for their ill spouses.

Some, despite disabling illnesses such as arthritis, continue to provide services to their families or to their communities.

Whereas in the past, being elderly may have been a legitimately dependent status, the current correlation between ageing and cost means that dependency is now a negative status.

Passive consumers: The view that people with chronic illness are passive is related to stereotypes of dependency on welfare payments and an inability to work in paid employment. It assumes that when people are not gainfully employed they are passive recipients of a range of services. This view ignores the activist roles in support and self-help groups most people with chronic illness pursue for a range of reasons. One reason is to optimise their health through self-management activities in support groups. Another reason is to share knowledge of the illness with peers, while a third reason is that self-help groups replace social contacts others access through workplaces. Finally, many people with chronic illness come together in support groups with the declared aim of improving the social status and the services of their fellow sufferers.

Non-compliance: Behavioural models, favoured by health-promotion strategies, draw parallels between chronic illness and poor health behaviours. Negative emphasis is placed on a small range of illnesses, including asthma, arthritis and diabetes, where there is a high correlation between individual behaviours and health status. Programs claim there can be a range of improvements from total eradication of the disease in the population to ameliorating the effects of the disease in individuals through compliance with a range of health strategies. When the term chronic illness is appropriated by the behavioural model, all chronic illnesses, regardless of their pathology, become associated with behaviour and compliance, even though those illnesses which are unrelated to behaviour receive no funding through such programs.

When individuals fail to adopt health-promoting strategies or comply with treatment regimes they are held responsible. At its best, this model attempts to address non-compliance through education and information and by exploring the relationship between social class and compliance. At its worst, individuals can be demonised, as may happen to people with tobacco smoking related illness.

Non-compliance is an area where the reality is far more complex, than the behavioural model suggests. Reasons for non-compliance are diverse and may range from differing value systems to holding different priorities in life. Different value systems include different interpretations of health and illness, different attitudes towards treatment and differing religious and cultural beliefs. Better understanding of the relationship between indigenous health and belief systems means that the accusations of non-compliance to health regimes by indigenous people now sounds simplistic.

However, in some cases, inability to comply is a reflection of the economic polarisation of people with chronic illness from the rest of society. A survey carried out by the Chronic Illness Alliance in 1997 found that many people with a range of chronic illnesses had difficulty in coping with the costs of their illness. This included people whose income exceeded \$40,000 per annum. In addition to costs of medication, medical and hospital visits, people with chronic illness had high expenses for utilities, domestic help, allied health care, nursing care, aids and equipment (which might include dressings, prostheses, wheelchairs or beds), special clothing, transport and housing modifications. Many people required additional medications not available on the PBS, such as analgesics, antifungal powders and vitamins. Still others considered complementary therapies were essential to maintaining their health. In some cases, consumers found their costs exceeded more than \$7000.00 per annum. In families where there were more than one person with a chronic illness an income of \$60,000.00 per annum was hard to budget on. The Consumers' Health Forum study, "The Costs of Chronic Illness" (1997) reported similar findings.

In order to cope with the drain on their incomes, people budgeted. They reported going without food and clothing, or going without heating. Social outings and holidays were rare luxuries. A common budgeting strategy was to stockpile medication, or reduce the prescribed amount. In some families, parents reported going without their own medication so they could afford their children's. Children were not able to participate in school camps and outings because of the costs. The cost of transport was always a consideration but people reported that it was necessary to maintain a vehicle in event of emergencies as well as for medical appointments. Other people reported that they had to make choices between treatments.

These research findings suggest that for people themselves, the issue is not one of compliance but a need to prioritise their needs in a situation where they confront scarce resources and a range of options. The strategies people with chronic illness and their families adopted to meet this complex situation demonstrates that they attempted to maintain their lives, of which their health was albeit an important part, but only a part.

Negative stereotypes survive in definitions when the social situations of people with chronic illness are oversimplified or excluded. Since chronic illness is experienced in a broad and changing social setting, definitions need to reflect this changing experience as well as changes taking place in treatments and care.

Conclusion

There is little agreement as to which attributes are most important in defining what constitutes a chronic illness. In biomedical literature pathological and biological markers are used as indicators. In nursing literature qualitative issues, such as the effects on a person's quality of life are seen as the definitive factors. In policy literature, social and behavioural issues predominate. However, these are all largely derived from the view that chronic illness can be measured in terms of persistence, insidiousness or intractability.

Definitional statements in all health literature tend to reflect the perspective of the writer and ignore the changes taking place for populations. They also objectify the experience of living with a chronic illness. This has two effects. The first is that it does not include the complex social and cultural situations in which chronic illness is experienced. Secondly, this means that people's behaviours are seen in stereotypical terms.

A greater understanding of the social and cultural factors in which chronic illness is experienced will lead towards a definition that encompasses both the changing nature of chronic illness and the need for policies which better meet the needs of people with chronic illness.

While the different perspectives concerning what constitute health and illness remain, it is unlikely that a uniform definition of chronic illness will receive universal acceptance. However debate around what should be included in such a definition would lead some way towards this and may also lead to a better understanding of the place of chronic illness in the world of health and illness, the services most suited to reducing its incidence and the effect it has on people's lives.

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