Constructions of chronic illness

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Abstract

Interest in chronic illness as an area for research and writing is increasing across a diverse range of disciplines. Initially of interest to medicine, chronic illness is now studied by social scientists, psychologists and health professions (for example, nurses). Predominantly, the individuals affected by particular chronic illnesses have been the central interest in the body of work relating to chronic illness. The physical, psychological and social effects of chronic illness feature as major emphases for distinguishing individual variations from the 'norm'. By exploring current constructions of the major perspectives of chronic illness discourses of normalisation, individualism and science are revealed as privileged and dominant in nursing practice. © 1998 Elsevier Science Ltd. All rights reserved.

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1. Introduction

Chronic illness has become increasingly prominent in developed countries as mortality rates from acute illness decrease in response to improved sanitation (Gerhardt, 1990) and public health surveillance (Strauss, 1984). Scientific explanations of chronic illness have focused on the person with chronic illness and developed within biomedical or psychosocial frameworks. Critical analysis of the literature discussing chronic illness provides an opportunity to reveal the discourses which underpin the models nurses have appropriated to guide their practice.

The work of French philosopher Michel Foucault (1970, 1972, 1975a,b, 1980) has been useful in the exploration of discourses central to the current constructions of chronic illness. Discourses, in a Foucauldian sense, refer to more than the language we speak. Discourses form the constraining grids that give rise to the ways in which we think and act. Therefore, they can be seen as framing the various subject positions and institutional practices we engage in. Our ways of knowing and being in the world are not simply governed by one discourse; we are influenced by many competing discourses. Foucault argued that power relations arise in the discursive practices which accompany the various discourses in which we are positioned. Power relations established within these discursive practices operate through various technologies of power. These technologies of power act to maintain the positioning of particular discourses as dominant. By reviewing of the broad range of research and theoretically based literature, discourses of individualism, science and normalisation are revealed as dominant in current constructions of chronic illness.

2. Biomedical approaches

Medical literature relating to chronic illness remains directed toward the investigation of pathophysiology of specific diseases and mechanisms for clinical treatment. The primary aim of treatment is to reverse, if possible, the course of illness and restore the patient to a normal state of health, thereby affecting a 'cure'. Where cure is not attainable, treatment becomes focused on minimising the impact of the disease on the body. This is primarily achieved through symptom control where treatment seeks to maintain a state that mimics normal health as much as possible. The focus on the mechanisms of the
disease within the body creates a view of the body as a physiological entity.

The medical approach toward exploration of any disease state begins when medical researchers are successful in attracting significant research funding for the investigation of physiological, pathophysiological, and clinical treatments. The accepted approach to medical research remains experimental, using 'normal' populations as controls. Controls in this way are used to contrast the disease state, to see the difference between the people with the disease state from the 'normal' individuals.

Research medicine, with a curative intent, fails to acknowledge a reality beyond the physical body of chronically ill people for whom cure is not attainable. A focus on the physical body in its abnormal state and the vigilant searching for cure has obscured the "care and dependency needs" of those with chronic illness (Cooper, 1990). Despite this, the biomedical approach to illness remains at the centre of constructs of chronic illness. Likewise, paramedical positions build from medical definitions of chronic disease seeking to supplement medical knowledge and explore common themes across disease groupings (Strauss, 1990).

3. Psychosocial approaches

Psychosocial approaches to chronic illness have developed from the medical view, seeking to determine the developmental 'threads' of chronic illness. These 'threads' are found in the social and psychological manifestations of chronic illness. Four major themes identified within the psychosocial area of inquiry are: manifestations of chronic illness, the 'mapping' of illness trajectories, the evaluation of quality of life, and the exploration of the notion of compliance.

3.1. Manifestations of chronic illness

Strauss et al. (1984) represented chronic illness as an experience of multiple problems that may change but do not go away. Chronic illness is marked by medical crises. The prevention and control of these crises require the construction of complex social arrangements to address the considerable psychological and social upheaval involved.

Chronic illness also creates a demand to manage treatment regimes. After evaluating the efficacy and value of the regimens, ill people often seek to supplement their regimes with alternative treatments. A major endeavour for a chronically ill person is symptom control, and regimen adherence was identified by Strauss et al. (1984) as a major means of attaining this. People with chronic illness were identified as reordering time; juggling the management of both their illness and their lives. A key strategy in living with chronic illness, according to Strauss et al. (1984), is normalisation. People hide and conceal their disease from others, trying to pass themselves as 'normal', an idealised notion of being the same as the rest of the presumably 'normal' population.

Lubkin (1986) extended this work by exploring the notions of stigma, altered mobility, body image and sexuality in relation to chronic illness. The psychosocial impact of these factors on individuals include lowered self esteem, anxiety and isolation. Lubkin identified a broad range of strategies for dealing with these manifestations, directed at both the ill person and health workers.

Hymovich and Hagopian (1992) explored manifestations of chronic illness through the concepts of stressors and potential stressors. They offered four major categories of stressors: the disease and its management; external and internal resources of the individual; relationships with family and others; and life style adjustment. In their view, chronic illness involves multiple and frequently changing stressors that individuals respond to in a variety of ways. This is a functionalist explanation of chronic illness, with an underlying goal of facilitating adaptation to the condition. Hymovich and Hagopian's model directs nursing interventions toward individual adaptation to chronic disease. White et al. (1992) also explored stressors and coping in chronic illness toward the promotion of effective psychosocial adaptation. These approaches support the view of nurses working toward normalisation, aiding individuals to find ways to lead as near normal a life as possible.

3.2. Mapping of trajectories

The second major area of psychosocial investigation has been the idea of 'illness trajectory' as a way of understanding the complex path of chronic illness (Glaser and Strauss, 1968). Trajectories have been explored from the perspective of those involved (the ill and the carers). Inherent in the use of the term trajectory are notions of direction, movement, shape and predictability, all related to time. The complexity of some illnesses, together with an increase in technological treatments, has influenced the magnitude and number of possible trajectories (Lubkin, 1986).

Mapping trajectories has been of interest to many with Rolland, (1987) providing insight into adaptation in chronic illness. He described four basic classifications that are key features in a typology of the psychosocial aspects of chronic disease: 'onset' the rate at which the disease occurs, 'course' of the disease categorised as either progressive, constant or relapsing/episodic, 'outcome' on life span and the 'degree of incapacitation'. Combining these classifications provides a map where specific diseases can be located.
Rolland, (1987) further identified three time phases as part of a matrix with the typology of illness to map possible trajectories of chronic illness. First, the ‘crisis’ phase referring to the period before and immediately surrounding diagnosis where learning to live with symptoms and illness-related demands takes place. Second, the ‘chronic’ phase, the time span between initial diagnosis and the final time phase—where the key task is “to maintain the semblance of a normal life under the ‘abnormal’ presence of chronic illness and heightened uncertainty” (Rolland, 1987). Third, the ‘terminal’ phase is marked by issues surrounding grief and death.

This model has been used to indicate norms in adaptation, where variation from ‘normal’ adaptation as maladaptive. Accompanying the use of a classificatory approach is the expectation that individuals will conform to predefined trajectories. Rolland’s model is firmly located within medical definitions and classifications of morbidity and prognosis.

Moving away from a classificatory approach, Strauss et al., (1984) argued that trajectories of illness were strongly linked to the ill person’s perceptions of events, as well as the physiological manifestations of the disease. Many diseases have fairly predictable trajectories, whilst other diseases are relatively uncertain. Whatever the trajectory, an ill person seeks to locate themselves within their trajectory. They are aware of the phases and changes in manifestations of their disease and reassess their personal trajectory, being vigilant of symptom change to track the course of their illness.

Register (1987), a person with a long standing chronic illness, used a descriptive approach to join with the voices of others experiencing chronic illness. Whilst her work is not presented as a trajectory, it provides a different view of the trail or journey experienced from diagnosis to the finding of new ways of living. This journey requires learning the politics of being an ill individual in a world of health centred people. Initially diagnosis of illness is a time of elation, where the ill person feels a legitimisation of their symptoms. Diagnosis provides a tangible position from which the ill person can relate to the problems they are experiencing. From the elation of having a name for their problem, many people move through a process of grieving for the loss of their health and lifestyle. They frequently experience a preoccupation with self.

After the initial diagnostic phase chronically ill people experience stigma, which is frequently reinforced through association with others who are chronically ill. Being labelled by the disease they experience and the treatments they use, people with chronic illness are set apart from others. The etiquette of chronic illness demands that chronically ill persons try to pass themselves as healthy. Social interaction with others constantly demands explanation of why the ill person is not the same as everyone else, why they look different, why they eat differently, why they walk or talk differently. The demand for explanation is a constant reminder of not being ‘normal’ (Register, 1987). Ill people try to create as near a ‘normal’ appearance as possible to reduce the degree of stigma experienced.

The voices that Register presents are set apart from the other works discussed above because they give an insiders’ view. Yet, this view is also embedded in the biomedical experience of illness and clearly articulates the pain arising from not being ‘normal’.

3.3. Assessing quality of life?

Given an understanding of the manifestations and trajectories of chronic illness investigators have sought to assess the quality of life of people experiencing chronic illness. Whilst ‘quality of life’ has been the focus of innumerable studies, the term remains vague and inconsistently defined (Fries and Spitz, 1990). Evaluation of the quality of outcomes of various available treatments has been the major impetus for the study of quality of life. Physical and occupational rehabilitation have been viewed as the primary indicators of quality of life in clinical research (Johnson et al., 1982).

There is increasing debate about the appropriate breadth of inquiry. Fries and Spitz (1990) argue that as medicine seeks cure and palliation of disease, a “health-oriented quality of life: those aspects that might be affected positively or negatively in... the clinical situation” are the context for investigation. This is a consistent view in studies of quality of life in dialysis patients (Johnson et al., 1982; Kaplan De-Nour and Shannon, 1980; Molzahn, 1991; Voepel-Lewis, Ketefian, Statt, and White, 1990) where issues of morbidity and mortality predominate. Burckhardt et al. (1989) argued that the equation of morbidity and mortality measures with quality of life is confused. They suggested that the subjective perceptions of persons with chronic illness need to be included if therapeutic interventions (both medical and nursing) are to enhance quality of life.

Assessing the quality of life of people with chronic illness has predominantly been the interest of clinicians seeking to determine if their interventions are successful. Success is measured according to the aspects of life that clinicians give weight to and using scales determined by professionals rather than ill persons. Whilst there is agreement that measuring quality of life is desirable, there remains little consensus about how this can be effectively achieved (Kaplan De-Nour, 1990; Burckhardt et al., 1989).

3.4. Compliance

Compliance with treatment has been the fourth major area of psychosocial inquiry relating to chronic illness. Health professionals’ view the successful management of chronic illness as reliant on patients’ adherence to
treatment regimens. Treatment regimens require patients to change the way in which they manage aspects of their life which range from very simple to extremely complex routines.

Compliance has been defined as “the extent to which a person’s behavior (with taking medication, following diets, or executing lifestyle changes) coincides with medical advice” (Haynes, 1979, cited in Hymovich and Hagopian, 1992). Compliance rates in chronic illness are estimated at approximately 50% (Cameron and Gregor, 1987; Turk and Rudy, 1991). Non-compliance has been noted as having severe consequences, including exacerbation and progression of disability (Turk and Rudy, 1991). A failure to follow treatment regimens results in patients needing emergency treatments, and hospitalisation to re-establish a stable condition (Lamping and Campbell, 1990). It has been argued that predicting the degree of compliance would allow clinicians to explore alternative strategies which would lead to increased patient compliance. Therefore the surveillance of compliance has become an important feature of clinical practice.

Physiological and biochemical tests are frequently used to measure compliance. Treatments are designed to maintain ideal biochemical and physical levels. Therefore, the degree of compliance is assessed by the proximity of a patient’s levels to these predetermined levels. However, variations in these levels may not always indicate ‘non-compliance’. Changes in the illness state and variability in the treatment may contribute to fluctuations from the expected (Lamping and Campbell, 1990).

Other attempts to explore compliance have examined the relationships between the health beliefs of the individual, the complexity of treatment, the available support systems and the personal characteristics of the ill person. These factors seem to be associated with compliance, but are poor indicators of the probable degree of compliance (Eddins, 1985).

Kontz (1989) argued that current definitions of compliance infer a relationship of authority and power of one individual (medical and health professionals) over another (the patient). She argued that compliance needs to be redefined to incorporate the patients’ right to choose not to adopt treatment regimens. However, in arguing for collaborative relationships yet retaining the language of compliance, there remains a failure to relinquish control by health care workers. The use of patient centred language by the nurse and the use of “interventions targeted at the cause of the compliance issues” (Kontz, 1989) suggests the continued desire to facilitate adherence to treatment. This supports the work of Kelly and May (1982) who identified the consequence of non-compliance by patients was to be labelled by health workers as ‘bad patients’.

There has been little investigation of patients’ views on issues relating to compliance. Patients evaluate and adopt treatments using social rather than health criteria, such as financial costs associated with treatment, family expectations, the personal relationship they have with their physician (Cameron and Gregor, 1987) and a belief in the effectiveness of the treatment (Turk and Kerns, 1985). Thorne (1990) identified two explanations patients give for non-compliance with treatments. First, self-protection arising from a distrust in the quality of decisions made by medical and health care workers about treatment. Second, the need to maintain relationships with health care personnel prohibits total withdrawal, so non-compliance serves as a strategy to exercise some control over the relationship.

4. Individualism, science and normalisation

Throughout the range of work relating to chronic illness, the discursive fields of individualism and science predominate. The ascendancy of these discursive fields is evidenced in both the methods employed to investigate chronic illness and the findings arising from the use of those methods. Discourses of normalisation are supported by and interwoven in both of these discursive fields.

4.1. Discursive field of individualism

Discourses of individualism value individual interests over collective interests, where individual autonomy is argued as sovereign. Notions of personal freedom, individual rights to self-determination and ownership have been privileged in western societies through the discursive field of the ‘individual’ (Abercrombie, Hill and Turner, 1986; Tesh, 1990). It is through the discursive practices arising in this field that individuals are constituted as separate, significant and, therefore, important in society. Accompanying the privileges of individualism are obligations to demonstrate responsibility for those individual actions. The freedom to self determination becomes tempered by notions of normal behaviour, where individuals are expected to conform to societal norms. In this way, subject positions created within discourses of individualism foster a perception that individuals are self-authoring or ‘sovereign’ with “our independent consciousness acting outside contingencies of history. We are also outside language and other interruptions” (Leach, 1992).

Within medical discourses, individualism predominates and can be seen in the focus of medicine with individual patients. The ‘patient’, not the person or their family, is the object of medical and nursing interest. Whilst the individual is positioned as important, this importance is limited to the individual as compared with a population of individuals, not with the individual as a person. In this way the notion of ‘individual’ acts as a
mechanism for control, as the use of surveillance and comparison with the 'average' individual reinforces expected norms. The responsibilities arising from the discursive practices of individualism for individual health facilitates shifting 'blame' for variance from these averages to the person displaying that difference (Lowenberg, 1995). Individuals become implicated in the cause of their illness because they are considered 'sovereign' or self-authoring.

The pervasive infiltration of discourses of individualism is exemplified in the dominance of the 'individual' as the basic unit of social analysis and interventions relating to health and illness. Health promotion and education have become strategies for the surveillance of individual compliance to expected norms and are used to show individuals the purported errors in their life choices that have led to ill health and urge for change in those choices. This view does not acknowledge a social context in which health is experienced (Tesh, 1990; Crawford, 1994; Lowenberg, 1995). Whilst individuals can seldom alter their social context, they accept this blame as if part of their discursive understanding of the responsibilities of an individual. Further, the family is also silenced by discourses of individualism, where the community and collective interests of society are marginalised by the centrality of the individual.

4.2. Discursive field of science

The discursive field of science is also evident as underlying the current views of chronic illness. Discourses of science are epitomised in the scientific method of inquiry which incorporates the ideals of objectivity, reliability, precision and validity, and privilege science over other ways of knowing.

Scientific discourses have therefore framed the development of the health professions and their work. The use of scientific method predominates in the vast body of literature relating to health care as evidenced in the disciplines of medicine and psychology which are grounded in scientific traditions. Knowledge in these disciplines arises out of inquiry which seeks to discover the facts and truths about the body and its behaviour. These 'facts' and 'truths' are presented as models and theories and reduce human experience to measurable phenomena. The work on chronic illness discussed in this paper typifies this approach to knowledge production, where authoritative biomedical models of illness have been created through scientific discourses. These models have become the basis from which other disciplines investigate. Research about chronic illness can be seen to have arisen from a medical construction of chronic illness where the subjects are the chronically ill patients who are positioned as the object of investigation through scientific discourses. Social sciences that seek to explore other factors relating to chronic disease are viewed as lesser sciences, and treated as peripheral to the central focus of understanding disease (Tesh, 1990).

Scientific discourses have become dominant in Western society where there is a predominant belief that science will provide the truth or the answers to any problems posed. The discursive practices arising from discourses of science have permeated most of the aspects of social life, creating an effect of unquestioning acceptance of the reductionist models which exclude subjective experiences. Discourses of science and individualism intersect as the individual occupies the central interest of the explanation of causation, manifestations and treatments of disease. The interplay between the discursive fields of science and individualism acts to reinforce their respective dominance in our society and therefore support the sanctions that arise when the 'norms' prescribed within these fields are not attained.

4.3. Normalisation

Discourses of normalisation are apparent in the exploration of chronic illness and are supported by the discursive fields of individualism and science. These discourses have been adopted by health care workers to promote subject positions or 'norms' for patients 'which are as culturally normative as possible, in order to establish and/or maintain personal behaviours and characteristics which are as culturally normative as possible' (Anderson, Elfert and May, 1989). These subject positions have arisen through the identification of a range of normal characteristics of populations gained from the wide spread use of surveys. Normal characteristics are determined from the statistically most common or usual occurrence of particular phenomenon in particular samples of population (Armstrong, 1987). When a person fails to demonstrate an expected norm they become viewed as abnormal, demonstrating a failure to adopt the subject positions prescribed for them. Responses to the failure of people to meet 'norms' can be to blame subjects for their 'abnormal' characteristics as discussed in relation to the discursive field of individualism or to help subjects to restore the 'norms' in their life.

Chronically ill people fall outside the expected 'norms' by their failure to restore themselves to 'normal' health. However, whilst they are viewed as 'abnormal', new subject positions emerge for this group of people within discourses of normalisation which see a different set of 'norms' emerge for acceptable characteristics within the illness state. Surveillance becomes an important strategy for health care workers to monitor patient compliance with these expected 'norms'.

Discourses of normalisation are reproduced through procedures directed at promoting the 'norm' and the accompanying use of sanctions when patients fail to comply with those procedures. Underlying the desire for normalisation is a drive to ensure people are productive
elements in society (Anderson et al., 1989) and health care workers have become agents in that quest. Discourses of normalisation have become dominant in the practice of health care workers, enshrining expectations of self-responsibility from individuals who are sick and/or disabled (Anderson et al., 1989).

5. Conclusion

Current constructions of chronic illness are grounded in the discursive fields of individualism and science. The medically produced view of chronic illness has become the foundation for most investigations of chronic illness and its consequences for those with chronic illness, their families, health care workers and society. This has resulted in the continuation of a predominantly narrow and paternalistic approach toward chronically ill people. Chronically ill people have become implicated as responsible for their illness through discourses of individualism. They have become both the object and subject of scientific investigation.

The dominance of positivist empiricism as the basis for understanding chronic illness has limited investigations to an exploration of the way illness occurs in individuals providing mechanisms for producing new 'norms' to emerge for those with illness. The 'person' (not the individual) with chronic illness has been isolated from scientific investigations and, as a consequence, families and social outcomes of long term illness have been minimised or frequently ignored.

Nursing's contribution to the vast body of literature relating to chronic illness is relatively small and has seen most nurses as positioned within the same discursive fields of science and individualism as medical and social researchers. The work of nurses can be seen as supporting the use of 'idealised norms' in attempting to facilitate the rehabilitation of patients with chronic illness. However, the discursive foundations of these 'norms' remain uncontested as nurses continue to endorse the dominant constructions of chronic illness.

References