A study into the use of and need for healthcare services, for HIV infected people, from diagnosis until death

Margaret I. Jamieson

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A study into the use of and need for healthcare services, for HIV infected people, from diagnosis until death.

A thesis presented in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

from University of Wollongong

by

Margaret I. Jamieson. BA(Glas.C.T) MPH (Dundee).

Department of Public Health and Nutrition.

1995.
I hereby declare that I am the sole author of this thesis. This thesis does not incorporate without acknowledgement any material previously published or written by another person except where due reference is made in the text.

Margaret I Jamieson.
ABSTRACT

The aim of this study was to determine the use of the healthcare system by people with HIV/AIDS, and to identify and compare variations in service provision to patients with similar needs, and variations between needs and service provision. The variations would suggest changes in service management in the interests of improvements in cost/effectiveness.

Central to health service management is the need for information. The primary hypothesis of this study is that information systems need to be refined to support management of AIDS/HIV as a chronic, infectious condition, from initial manifestation through to death. It is hypothesized that it is impractical to manage healthcare delivery without recognition of the disease processes and changes in social factors over the duration of the disease; or without taking account of the links between episodes of care, and the extent of care management and access.

This was a longitudinal study, which involved two hundred and ninety-two HIV infected respondents. Respondents entered the study through networking, all volunteered. The study duration was from March 1993 until March 1994. In addition to these recipients of care, interviews were undertaken with service providers. This information was used to corroborate the findings of those persons who were HIV infected. Although limited by issues such as volunteer bias, small numbers and an inability to access clinical records, the study produced much useful information. It was possible to ascertain health service utilization for a group of individuals who exhibited a wide range of symptoms. The study also demonstrated the difficulties of accessing a heavily researched group and in maintaining contact over a long period of time. The patient population was highly mobile
in seeking and accessing healthcare. This mobility is reflective of the problems of confidentiality, unmet need within an area and patient choice.

The main findings of the study demonstrated that people sought healthcare from a wide variety of sources. There was considerable use of voluntary and statutory services. Service utilization was influenced by specific demographic features such as living alone, being a professional and using a private physician and/or general practitioner as their main source of care. A series of ten levels of HIV infection, from diagnosis through to death, were identified. The levels indicate increasing disease severity and increasing healthcare needs. One trend from this study suggests that the bulk of care is happening in the community with a heavy involvement of voluntary carers. The involvement of a significant number of agencies in the delivery of care impacts upon costs and co-ordination of care. There are substantial costs involved including personal costs that were beyond the scope of this study to evaluate. Whilst the use of Diagnosis Related Groups is applicable to the estimation of hospital costs, given the trend towards community care, it is important to develop a series of cost measures that incorporate community as well as hospital costs.

The findings of the study suggest that there is an urgent need to develop a structured approach to co-ordination of care. A development of a series of cost measures that incorporate community and hospital cost is required. Whilst there is no such thing as a typical patient, it is possible to identify a series of phases of HIV infection with levels of severity. Each stage indicates a differing need for and use of healthcare services. The importance of collecting demographic data was reinforced. It was possible to show that for this group of HIV infected people, certain factors, were implicated in the frequency and use of healthcare services. The need for additional services was brought to the fore, particularly services relating to specialized home care and community psychiatric support.
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