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1995

## 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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Table of Contents

Title page i

Statement of Authorship ii

Abstract iii

Acknowledgements v

Table of Contents vii

List of Tables x

List of Figures xii

Chapter 1

Introduction..... 1

1.2 Origins of the research.....4

1.3 Study Objectives .....6

1.4 Formal statement of the research hypotheses. ....7

1.5 Thesis Structure 8

Chapter 2 The Nature of AIDS / HIV Infection.

Overview..... 11

2.1 The Nature of AIDS / HIV Infection..... 14

2.2 Transmission of the Virus..... 17

2.3 Disease Progression. .... 24

2.3 Global Patterns of the HIV Epidemic.....	26
2.4 Infection in Australia.....	28
2.5 Clinical Management.....	32
2.5.1 The Range of HIV Infection.....	32
2.5.2. Management of HIV Infection. ....	37
2.6 Case Management.....	40
2.7 Conclusion.....	45

### **Chapter 3 Social perceptions of AIDS and the subsequent impact on policy development.**

Overview .....	47
3.1 The Perceptions of AIDS and the resultant impact on Health Services. ....	50
3.2 The Plague of the Twentieth Century ?.....	52
3.3 AIDS as a Chronic Disease. ....	60
3.4 AIDS as a Chronic Infectious Pandemic. ....	64
3.5 Response of the Health-care Services. ....	67
3 6 Current Service Responses in Australia .....	72
3.7 Australian Federal Response to AIDS/HIV .....	74
3.8 Health Service Response in New South Wales.....	77
3.9 Conclusion.....	80

### **Chapter 4 Health Service Access, Use and Costs.**

Overview .....	82
4.1 Access to services.....	85
4.2 Utilisation of Health Care Services. ....	92
4.3 The Costs of AIDS/HIV.....	98
4.3.2 Case-mix and Diagnosis Related Groups.....	99
4.3.3 Costing Studies .....	104
4.4 The Impact on the HIV Infected Individual. ....	109

4.5 Conclusion.....	112
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## **Chapter 5 Method**

Overview .....	114
5.1 Design Issues.....	117
5.1.1 The measurement of need, cost and the utilisation of healthcare as a basis for service planning.....	117
5.1.2 Research context.....	119
5.1 3. Research Participation.....	120
5.1 4.Data Capture.....	124
5.1.5 Confidentiality. ....	131
5.5 Study Method.....	136
5.3.1 The recipients of healthcare--People with HIV/AIDS .....	137
5.3.2 Health Care Providers.....	138
5.4 The data collection instruments and their construction.....	139
5.4.1 The Client Questionnaire.....	139
5.4.2 The Interview Schedule.....	142
5.5 Method of analysis.....	143
5.6 Conclusion.....	145

## **Chapter 6 The Pilot Study**

Overview.....	147
6 1 Study Design.....	149
6.2 The Interviews of Service Providers.....	149
6.2 (a) Data Collection: the Interview Schedule.....	149
6.2 (b) The Sample.....	150
6.2 (c)Method of data capture. ....	150
6.3 Data Analysis of the Interviews .....	150

6.4 Interview Findings.....	151
6.5 Self -Enumeration Questionnaire for AIDS/HIV Patients.....	163
6.6 Results.....	165
6.6.2 Clinical Characteristics of the Sample.....	169
6.6.2(a) The Results from the Mental Health Questionnaire.....	169
6.7 Discussion .....	188
6.8 Conclusion.....	193

## **Chapter 7:Results**

Overview.....	194
Part 1:The Interviews of Service Providers.....	197
7:2 (a) The interview schedule:data collection	197
7:2(b) The Sample.....	197
7:2 (c)Method of data capture. ....	198
7:3 Data Analysis of the Interviews.....	199
7:4 Interview Findings.....	200
7 Part 2:The results of the self-enumeration questionnaire.....	221

## **Chapter 8:Discussion and Conclusions.....**

8.1 Discussion of the results of the study.....	252
8.2 Limitations of Study .....	266
8.3 Areas for future research.....	272
8.4 Conclusions.....	273

## **References .....277**

## **Appendices. 315**

Appendix 1. Data elements.	316
Appendix 2. Pilot and main study: Cover letters, Consent forms & Questionnaires.	317
Appendix 3 Interview Schedule.	339

List of Tables

Chapter/Table.

2.1 Sexual transmission of HIV. .... 19

2.2 CDC Clinical Classification..... 33

2.3 The range of HIV infection ..... 36

  

6.1 Demographic characteristics .....166

6.2 Knowledge of HIV Status .....168

6.3 Frequency of Total Mental Health Scores on the 28-Item General Health  
Questionnaire.....170

6.4 Frequency of scores on the 28 -Item General Health Questionnaire.....171

6.5 Reported Drug use in relation to treatment of Opportunistic Infections.....173

6.6 The source of Alternative therapies used in the pilot study.....177

6.7 Distribution of HIV/ AIDS Cases by AN-DRG .....  
The Sample Compared to NSW 1990/91 Figures. ....179

6.8 HIV-DRG Average Length of Stay (ALOS) (in days).....181

6.9 Cost of Inpatient care using HIV /DRG cost weights as per Palmer et al  
(1993).....184

  

7.1 Interview participants and their work designation.....198

7.2 Reasons for Attrition.....222

7.3 Marital and Co-habitation status.....224

7.4 Knowledge of HIV Status (by others).....226

7.5 Frequency of Total Mental Health Scores on the 28-Item General Health  
Questionnaire.....227

7.6 Frequency of scores on the 28 -Item General Health Questionnaire.....229

7.7 Prevalence of signs and symptoms among the 205 respondents who experienced symptoms. ....	231
7.8 Reported Drug use in relation to treatment of Opportunistic Infections.....	233
7.9 Sources of Alternative therapy used by respondents.....	239
7.10 Distribution of HIV/ AIDS Cases by AN-DRG	
The Sample Compared to NSW 1990/91 Figures. ....	241
7.11 HIV-DRG Average Length of Stay (ALOS) (in days) ....	243
7.12 Cost of Inpatient care using HIV /DRG cost weights as per Palmer et al (1993).....	246
8.1 Descriptive Indicators of Disease Progression and Health Care Use /Need	253

## List of Figures.

### Chapter/Figure.

6.1 Age range of participants	166
6.2 The pattern of distribution through the DRG groupings by individuals over the pilot study.	180
7.1 The pattern of response from participants during the study.	221