

CHARACTERISTICS OF ADULTS

WITH ADVANCED HIV/AIDS

REFERRED TO COMMUNITY NURSES

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This thesis is submitted as partial fulfilment
of the requirements of a Master of Nursing (Research) Degree
in the Faculty of Health Sciences at the
Australian Catholic University
SYDNEY, Australia.

March 2001

Declaration

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No other person's work has been used without due acknowledgment in the main text of the thesis.

This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

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Signature 

Date 27/7/01

ACKNOWLEDGMENTS

I sincerely thank Dr Brian Bicknell (my Supervisor throughout the duration of this project), and Dr Lyn Coulon (my Supervisor since 2000), for their professional guidance and support. They have facilitated not only the creation of this thesis, but also my professional and personal development. In addition, I would like to thank Ms Deborah Burke and Dr Marianne Wallis, my previous Supervisors, Ms Barbara Hilliard and Ms Elaine Rutherford who also supported me with this process.

I would like to take this opportunity to express my gratitude to the many staff of the South Eastern Sydney Area Health Service who assisted me by offering their professional and personal support. I specifically acknowledge Ms Pam Brissett, Ms Jan Woods and Mr Malcolm Stokes of the Generalist Program based at Royal South Sydney Community Health Complex, for permitting my access to and use of facilities, in addition to approving requested periods of leave. I thank also the Cavell Trust who, through the New South Wales Nurses Association, awarded funds that allowed me to take leave from my employment to focus on my research activities.

I particularly wish to thank my wonderful daughter, Ellouise, for her support and tolerance throughout the duration of the study which has taken place during her important adolescent and young adult years. I have also been blessed with wonderful friends and colleagues who have assisted my journey, and would particularly like to thank Ms Patrizia Fiorillo, Ms Sally MacPherson, Ms Mary-Anne Ford, Ms Suzanne Ryan and Ms Pam Johnston. Finally, special thanks to my close friends and those family members who believed in my abilities, valued my efforts to attain this goal and offered their sustained encouragement throughout the project.

ABSTRACT

Characteristics of Adults with Advanced HIV/AIDS Referred to Community Nurses

Community nurses have a critical role in caring for people and families affected by HIV/AIDS in the home setting. Despite this, there is a dearth of Australian literature describing the health needs of these clients who are referred to them.

This study identified the demographic, clinical and psychoemotional aspects of adult clients with HIV/AIDS in Sydney, Australia, who were referred to community nurses and died between 1993 and 1995. Retrospective data from the records of 73 clients identified on 171 Community Nursing Referral Forms completed within the study period from an inpatient HIV/AIDS Unit was analysed using descriptive statistics and content analysis.

The sample was demographically similar to the general population of people with HIV/AIDS during the study period. The most commonly identified clinical aspects of clients included oral candida, mycobacterium avium complex, anaemia, drug intolerance, cytomegalovirus, pain, fever, diarrhoea, weight loss and cough. The most commonly identified psychoemotional variables were depressed mood, anxiety, grief and non-adherence to suggested interventions, with the most common emergent theme being the physical effects of HIV/AIDS illness. Emotional support, symptom monitoring and home assessments were the most common requests made of community nurses.

The study sample represented 14% of people who died following AIDS in New South Wales during this known peak period of AIDS diagnoses and deaths following AIDS. As a result of this study, documentation exists describing the characteristics of clients with advanced HIV/AIDS referred to community nurses. Current and future clients with advanced HIV/AIDS referred to community nurses may experience a similar clinical picture to that identified in this study. The findings can be used to reveal relationships amongst the key variables; lay the foundation for further comparative, theory or hypothesis driven studies; and demonstrate how this influences the community nursing role, strategies, interventions and outcomes.

TABLE OF CONTENTS

CHAPTER ONE: Introduction to the Study

1.1	Introduction to the Study	1
1.2	Study Background	1
1.3	Statement of the Problem	2
1.4	Study Justification	3
1.4.1	HIV/AIDS Incidence	3
1.4.2	The Link Between Hospital Discharge Planning and Community Nursing	5
1.4.3	Nursing Knowledge Deficits and Research Needs	7
1.5	Study Purpose	9
1.6	The Research Questions	10
1.7	Study Significance	10
1.8	Outline of the Thesis	12
1.9	Conclusion to Introduction	12

CHAPTER TWO: Literature Review

2.1	Introduction	13
2.2	Background to Community Nursing Role	13
2.3	Background to the HIV/AIDS Disease	14
2.3.1	Historical Background to HIV/AIDS Pandemic	14
2.3.2	The Human Immunodeficiency Virus	16
2.3.3	Classification of HIV Disease	17
2.4	HIV/AIDS Demographics	18
2.4.1	The Incidence of HIV Infection, AIDS and Death in Australia and New South Wales in 1993, 1995 and 2000	19

2.4.2	Gender of PLWHA	22
2.4.3	Country of Birth of PLWHA in Australia	24
2.4.4	Age of PLWHA	24
2.4.5	Exposure Categories of PLWHA	26
2.5	Clinical Aspects of PLWHA	28
2.5.1	HIV/AIDS Disease	28
2.5.1.1	Progression of HIV Disease	28
2.5.1.2	The Incidence of HIV - Related Illnesses	31
2.5.1.3	Gastrointestinal Disease	32
2.5.1.4	Respiratory Disease	36
2.5.1.5	Integumentary Disease in PLWHA	36
2.5.1.6	Haematological Disease in PLWHA	37
2.5.1.7	Malignancy in PLWHA	37
2.5.1.8	Neurological Disease in PLWHA	38
2.5.1.9	Eye Disease in PLWHA	40
2.5.1.10	Bacterial Infections in PLWHA	41
2.5.1.11	Musculoskeletal Disease in PLWHA	41
2.5.1.12	Other Physical Clinical Conditions	42
2.5.2	Psychiatric Disorders in PLWHA	42
2.5.2.1	Depression in PLWHA	43
2.5.2.2	Other Psychiatric Conditions of PLWHA	44
2.5.3	Signs and Symptoms of PLWHA	45
2.5.3.1	Pain Experienced by PLWHA	46
2.5.3.2	Other Symptoms Experienced by PLWHA	50
2.5.4	Drug Allergies and Intolerances Experienced by PLWHA	52
2.6	Lifestyle and Psychosocial Aspects of PLWHA	53

2.6.1	Employment, Income and Accommodation of PLWHA	53
2.6.2	Sexuality and PLWHA	54
2.6.3	Substance Use and PLWHA	55
2.6.4	Psychosocial Aspects of PLWHA	56
2.6.5	Social Supports and PLWHA	58
2.7	Psychoemotional Aspects of PLWHA	60
2.7.1	Depressed Mood in PLWHA	64
2.7.2	Distress and Anxiety in PLWHA	66
2.7.3	Grief Issues Experienced by PLWHA	68
2.7.4	Lack of Adherence to Suggested Interventions by PLWHA	69
2.8	Health Care Needs of PLWHA	70
2.8.1	Palliative Care of PLWHA	75
2.8.2	Discharge Planning of PLWHA	77
2.8.3	The Community Nursing Role in Caring for PLWHA	79
2.9	Conclusion to Literature Review	87

CHAPTER THREE: Methods

3.1	Introduction	89
3.2	Research Design	89
3.3	The Research Setting	91
3.3.1	The Process of Community Nurse Referral of Clients	91
3.4	The Sample	94
3.5	Data Collection	97
3.5.1	Instrument Development	97
3.5.1.1	Piloting of the Instruments	99
3.5.2	The Data Collection Process	100

3.5.3	Data Entry	101
3.6	Data Analysis	101
3.6.1	Quantitative Analysis	102
3.6.2	Qualitative Analysis	103
3.6.2.1	The Units of Analysis, Category Development and Coding of Data	105
3.7	Ethical Considerations	106
3.7.1	Consent	107
3.7.2	Confidentiality of Data	109
3.7.3	Dual Roles Experienced by the Researcher	110
3.8	Limitations of the Methodology	111
3.9	Conclusion to Methods	114

CHAPTER FOUR: Results

4.1	Introduction	115
4.2	Client Demographic and Socioeconomic Aspects	115
4.2.1	Client Demographics	115
4.2.2	The Clients' Home Environment and Living Arrangements	117
4.2.3	The Clients' Lifestyle	119
4.3	The Clinical Aspects of Clients	124
4.3.1	The Clients' Past Clinical History on Referral to Community Nurse	128
4.3.2	Recent Signs and Symptoms of Clients	131
4.3.2.1	Pain	132
4.3.3	Clients' New Diagnoses and/or Reasons for Admission to the HIV/AIDS Unit	135
4.4	Associations of Selected Clinical Variables	138
4.4.1	New Diagnoses/Reasons for Admission and Signs and Symptoms	138

4.4.2	Pain Sites and New Diagnoses/Reasons for Admission, Pain Symptoms and Pain Diagnoses	142
4.4.3	Pain Diagnoses and Pain Symptoms	144
4.4.4	Selected Diagnosis, Symptom and Psychoemotional Status Variables Common to HIV Encephalopathy	144
4.4.5	Variables Identified to Coexist Most Frequently	147
4.5	The Ongoing Issues and Continuing Treatments on Referral	148
4.6	The Physical Abilities of Clients on Referral	153
4.7	The Psychoemotional Status of Clients	157
4.7.1	Emergent Categories	159
4.7.1.1	Despondent/Depressed Mood	161
4.7.1.2	Distress/Stress/Anxiety	162
4.7.1.3	Grief Issues	165
4.7.1.4	“Non Compliant/Uncooperative”	166
4.8	The Requests of Community Nurses on Referral	167
4.9	Conclusion to Results	169

CHAPTER FIVE: Discussion

5.1	Introduction	170
5.2	The Demographic, Clinical and Psychoemotional Aspects of Clients	170
5.2.1	The Clients Demographics, Home Environment and Lifestyle	170
5.2.2	Clinical Aspects of Clients	178
5.2.3	Psychoemotional Aspects of Clients	197
5.3	The Associations Between the Most Commonly Identified Clinical Aspects	207

5.4	Emergent Themes from the Most Commonly Identified Psychoemotional Status Aspects	209
5.5	The Requests made of Community Nurses on Referral	210
5.6	Conclusion to Discussion	216

CHAPTER SIX: Conclusion

6.1	Introduction	217
6.2	Broad Conclusions from the Study	217
6.3	Implications for Community Nursing Practice	222
6.4	Strengths of the Study	225
6.5	Limitations to the Study	226
6.6	Opportunities for Further Research	227
6.7	Conclusion	228

REFERENCES	230
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LIST OF TABLES

2.1	Percentage of Total HIV/AIDS Cases in Adults and Children Reported to the World Health Organisation by Continent and Year	16
2.2	Reported Cases of Total Australian and NSW HIV Infections, AIDS Diagnoses and Deaths Following AIDS During the Study Time in 1993, 1994, 1995 and 2000.	20
2.3	Reviewed and Adjusted Reported Cases of Total Australian HIV Infections, AIDS Diagnoses and Deaths Following AIDS for Years of 1993, 1994, 1995 and 1999	21
2.4	HIV Infections, AIDS Cases and Deaths in Australia and NSW by Gender During the Study Time, 1993-1995 and 2000	23
2.5	HIV Infections, AIDS Cases and Deaths in Australia by Age During the Study Time, 1993-1995 and 2000	25
2.6	Deaths Following AIDS in Australia by Exposure Category During the Study Time, 1993 – 1995 and 2000	27
2.7	AIDS Cases by AIDS-defining Condition During the Study time, 1993-1995 and 1997-1999	32
2.8	Documented Characteristics of Pain in PLWHA	48
2.9	Documented Studies of Pain in PLWHA	49
2.10	Documented Problems in the Pain Management of PLWHA	50

2.11	Some documented Predictors and Influences of Psychological Signs and Symptoms of PLWHA	62
2.12	Some Documented Causes, Indicators and Predictors of Depressed Mood in PLWHA	66
2.13	Documented Causes and Predictors of Distress in PLWHA	67
2.14	Documented Factors which could Influence PLWHA's Acceptance of Suggested Interventions	71
2.15	Documented Activities, Needs and Issues of PLWHA in the Home	82
3.1	The Number of Times Clients Were Referred to Community Nursing Services During the Study Period	96
4.1	The Incidence of Conditions Previously Experienced by Clients on Referral by HIV Category	129
4.2	The Clients' Previously Experienced Conditions on Referral	130
4.3	The Signs and Symptoms of Clients	132
4.4	Conditions Causing Clients Pain	133
4.5	Sites of Pain Amongst Clients	134
4.6	Total Incidences of New Diagnoses or Reasons for Admission to the HIV/AIDS Unit	135
4.7	The Reasons for Admission or New Diagnoses of Clients on Admission to the HIV/AIDS Unit	137
4.8	Coexistence of Commonly Identified New Diagnoses/Reasons for Admission and Commonly Identified Symptoms	139

4.9	Coexistence of Commonly Identified Pain Sites with Commonly Identified New Diagnoses or Reasons for Admission, Pain Symptoms and Pain Diagnoses	143
4.10	Coexistence of Commonly Identified Pain Symptoms and Commonly Identified Pain Diagnoses	145
4.11	Coexistence of Conditions Common to HIV Encephalopathy	146
4.12	Variables of Clients Indicated by the Study to Coexist Most Frequently	147
4.13	The Psychoemotional Status of Clients	158
4.14	Psychoemotional Variables Explored Using Content Analysis	159
4.15	The Categories Emerging From Psychoemotional Status Variables	160

LIST OF FIGURES

3.1	An Overview of The Sample Displaying Clients who were Initial Referrals and Clients With Missing Data	95
3.2	The Composition of the Sample	97
4.1	The Age of Clients on Referral 1	116
4.2	The Distribution of Country of Birth of All Clients	116
4.3	The Distribution of Area Health Service on Referral 1 of All Clients	117
4.4	Who the Client Lived With on Referral 1	118
4.5	The Designated Contact Person of the Client on Referral 1	119
4.6	The Telephone Status of Clients During the Study Period	120
4.7	The Pension Status of Clients	120
4.8	The Known Sexuality of Clients	121
4.9	The Known and Deduced Sexuality of Clients	122
4.10	Unprescribed Substance Use Amongst all Clients	123
4.11	The Current ‘Social’ Alcohol and Nicotine Use of all Clients	123
4.12	The Age at HIV Diagnosis of all Clients	124
4.13	The Age at Death of all Clients	125
4.14	The Approximate Time Between HIV Diagnosis and Initial Referral	125
4.15	The Years Between HIV Diagnosis and Death Amongst all Clients	126
4.16	The First Stated CD4 Count of All Clients and Initial Referrals	127

4.17	The Drug Allergies or Intolerances of All Clients and All Referrals	128
4.18	Ongoing Issues on Referral of all Clients	148
4.19	Ongoing Issues on Referral of All Referrals and Initial Referrals	149
4.20	Ongoing Treatments Of All Clients on Referral	150
4.21	Ongoing Treatments on Referral Amongst all Referrals and Initial Referrals	151
4.22	Ongoing IV Therapies on Referral Amongst All Clients	152
4.23	Ongoing IV Therapies on Referral Amongst All Referrals and Initial Referrals	152
4.24	The Clients' Mobility Status on Referral 1 of All Clients	153
4.25	The Clients' Mobility Status Amongst All Referrals and Initial Referrals	154
4.26	The Clients' Abilities to Attend to Their Personal Care on Referral 1 of All Clients	155
4.27	The Clients' Abilities to Attend to Their Personal Care Amongst All Referrals and Initial Referrals	155
4.28	The Clients' Abilities to Perform Household Duties on Referral 1 of All Clients	156
4.29	The Clients' Abilities to Perform Household Duties Amongst All Referrals and Initial Referrals	157
4.30	The Broad and Specific Categories of Despondent/Depressed Mood	163
4.31	The Broad and Specific Categories of Distress/Stress/Anxiety	163
4.32	The Broad and Specific Categories of Grief	165

4.33	The Broad and Specific Categories of ‘Non-Compliant/Uncooperative’	166
4.34	The Requests Made to Community Nurses Amongst All Referrals	168
4.35	The Requests Made to Community Nurses Amongst Initial Referrals	169

APPENDICES

Appendix A	Australian National Council on AIDS Bulletin 18
Appendix B	Community Nursing Referral Form
Appendix C	Data Collection Form (3)
Appendix D	Data Collection Form Guide (3)
Appendix E	Comments During Data Collection (4)
Appendix F	Codes for HIV-Related Illnesses
Appendix G	Data Collection Form (1)
Appendix H	Response from ACU Research Projects Ethics Committee
Appendix I	Response from SEH Nursing Research Committee
Appendix J	Response from SEH Research Ethics Committee
Appendix K	Response from AIDS/Infectious Diseases Branch, NSW Health

CHAPTER 1

INTRODUCTION

1.1 Introduction to the Study

This chapter provides a brief background to the study, the research problem, aims and significance of the study. The purpose of this chapter is to introduce the reader to the thesis and the study, thereby setting the scene for the following chapters.

1.2 Study Background

Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome (HIV/AIDS) was identified as a significant and fatal health problem in Australia in the early 1980s, predominantly affecting homosexual men (Kaldor & Rubin, 1994). HIV/AIDS has impacted greatly on the well-being of patients, families and service providers world wide, and nurses are at the coalface providing care to these groups (Gilyard Brewington, 1994). Nursing services are vital to the care of people living with HIV/AIDS (PLWHA) and they are cared for in various settings which include hospitals, outpatient clinics and their homes (Meeks-Festa, McCarthy Uhle, Munjas, Gerszten & Creger, 1994).

The need for effective health care services increased with the incidence of HIV/AIDS (Ungvarski, Schmidt & Neville, 1994) and meeting the acute care needs of PLWHA was found to be expensive (Arkell, 1993; Sharp, Coleman, Starling, Cline & Rehm, 1991). Although most care offered was initially hospital based, the potential advantages of community based care were identified (Layzell & McCarthy, 1993) and it was acknowledged that PLWHA could be managed safely and effectively in the home environment (Moons, Kerkstra & Biewenga, 1994; Salyer, Waters & Yow, 1987;

Schmidt, 1992). The delivery of home based health care services was historically based on the premise that this would be more comfortable and cost effective compared to the hospital setting (Foley, Fahs, Eisenhandler & Hyer, 1995; Salyer et al.; Wright, Henry, Holzemer & Falknor, 1993). The majority of PLWHA prefer to be cared for at home (McCormick, Inui, Deyo & Wood, 1991) and it is considered to be a healthier environment than most hospitals due to the generally decreased risk of exposure to infections (Carney, 1990). Community nurses therefore, as primary health care workers, have a critical role in supporting the clients and families affected by HIV/AIDS in their homes (Arkell; Australian Community Health Association [ACHA], 1991; Kuehnert, 1991; Moore & Appleby, 1993; Schmidt).

1.3 Statement of the Problem

The study problem is as follows:

- ◆ Little is known, particularly in Australia, about the characteristics and home nursing care needs of PLWHA referred to community nurses.
- ◆ Although the medical treatment for PLWHA has improved, there remains a deficit of community nursing knowledge regarding the long term care of PLWHA.
- ◆ As far as can be ascertained, an Australian data base identifying the demographic, clinical and psychoemotional aspects of PLWHA does not exist. Demographic aspects include an overview of the clients' gender, age, residential environment and socio-economic status. Clinical aspects refer to the clients' physical manifestations, for example symptoms and diagnoses; in addition to clinical interventions. Psychoemotional aspects refer to the clients' psychological and emotional status. As these aspects form the basis of nursing assessments, they are necessary to identify the community nursing care needs of these clients.

1.4 Study Justification

1.4.1 HIV/AIDS Incidence

HIV/AIDS continues to have a significant impact on the health of the worldwide population. In 2000 it was estimated that globally, there were 5.3 million people newly infected with HIV and 3 million deaths following AIDS. At the end of 2000, there were an estimated 36.1 million people living with HIV/AIDS and a total number of 21.8 million AIDS deaths since the beginning of the epidemic (Joint United Nations Programme on HIV/AIDS/World Health Organisation [UNAIDS/WHO], 2000).

Although people with AIDS in Australia only represent 0.5% of the world wide population with AIDS (WHO, 1999), it has significantly affected the health of people in Australia with 5,946 deaths following AIDS reported cumulatively to the end of September, 2000 (National Centre HIV Epidemiology and Clinical Research [NCHECR], 2001). The majority of HIV infections, AIDS cases and deaths following AIDS have been reported in Sydney, New South Wales (NSW), followed by Victoria and the Australian Capital Territory (Kaldor et al. 1993). The transmission of HIV in Australia has mainly been through sexual contact between men (84% of infections) and this continues to be the case for current new infections (NCHECR, 2001).

In Australia, the rate of people reported with HIV infections has gradually decreased from a peak in 1985 (Law, McDonald & Kaldor, 1996) when the HIV antibody testing initially became available. This appears to be related to the success of harm minimisation practices amongst men who have sex with men and injecting drug users (IDUs) (NCHECR, 2000b; Pethebridge & Plummer, 1997). The Australian annual incidence of people newly diagnosed with AIDS rose sharply until 1988 when this increase slowed, peaking with deaths following AIDS in 1994 (955 and 735 respectively).

Since this time, the incidence has significantly declined with the introduction of effective antiretroviral therapy in the mid 1990s (NCHECR, 2000b). In the year ending 30 September, 2000, there were 177 people newly diagnosed with AIDS and 119 people who died following AIDS in Australia (NCHECR, 2001).

Despite this decreased incidence, it is estimated there were over 12,000 people living with HIV infection in Australia at the end of 1999. By 2003, it is projected this figure will rise to 13,520 and the annual incidence of new AIDS diagnoses will remain steady as long as the current benefits of antiretroviral therapy continue. It is also predicted that the number of people with AIDS who have a CD4 count of less than 500 will increase between now and 2003, and those with a CD4 count of above 500 will decline (NCHECR, 2000b).

While the incidence of AIDS in 1994 reflected the impact of HIV infections that occurred ten years previously (Stanley, 1994) this is not the case today. The use of the current incidence of HIV infections and estimated new HIV infections is preferred over the current incidence of AIDS as a predictor of future projections of the HIV/AIDS epidemic. This is because the variance in survival time and improvement of medical treatments can be misleading (Hendriks et al. 1993).

There was an estimated 748 new HIV infections in Australia within the 12 month period ending 30th June, 2000 with approximately half of these in NSW (NCHECR, 2000a). Alarming, new HIV infections have been seen to increase in Sydney, New South Wales since 1999. The Sydney Gay Community Periodic Survey (2000) (as cited in NCHECR, 2000a, 2000b) has identified a steady increase in unprotected anal intercourse with casual partners from 14% of respondents in 1996 to 32% in 1999. Furthermore, it is estimated that 33% of people with HIV infection in

Australia are currently not taking antiretroviral therapy (NCHECR, 2000b). Approximately 50% of people newly diagnosed with AIDS in 1999 were only diagnosed with HIV infection in the preceding three months. This has resulted in twice the number of new AIDS cases in people with late diagnosis HIV infection since the mid 1990s (NCHECR, 2000b). These figures indicate that Australians cannot afford to become complacent about HIV infection and its impact due to the reduced incidence of AIDS and deaths following AIDS.

Despite the current predictions, the future maintenance of the health and safer practices of PLWHA, in addition to the actual incidence of new HIV infections, AIDS diagnoses and related deaths within the Australian population is unknown. It could be argued that the incidence of new diagnoses of HIV infection and AIDS is likely to rise, particularly in Sydney, NSW.

It could be expected that people with advanced HIV/AIDS illness associated with severe immunocompetence today would exhibit a similar clinical picture to those experiencing this stage in the mid 1990s when the peak of AIDS diagnoses and deaths following AIDS occurred. It is this peak period of 1993-1995 that is the chosen time period for this study. It is important to counteract any complacency that may have occurred in Australia, and continue investigations in the area of nursing care of clients with advanced AIDS.

1.4.2 The Link Between Hospital Discharge Planning and Community Nursing

With the general trend in the Australian health system towards shorter hospitalisations (Reedy & Bragg, 2000), continuity of care between hospital and community is becoming increasingly vital. Bridging of the gap

between hospital and community service providers through effective liaison and, ideally, face to face contact and ongoing communication and support throughout the continuum of care is important (Carnegie & Rutter, 1992).

The discharge of a client with HIV/AIDS is a vital nursing task and the discharge planner acts as a client advocate and liaison person (Delaney, Albert & Meredith, 1994). Implications for continuing care after discharge, in addition to increased demand on community resources, is improvement in the outcomes of treatment and the quality of life and satisfaction of the client, their family and carers (Armitage, 1995). Liaison between the community nurse and the hospital based discharge planner can greatly assist this process (Armitage; Chalmers, Hartwig, Cook & O'Brien, 1991) and the complex nature of HIV/AIDS disease makes the successful collaboration of these services particularly important to client outcomes (Moons et al., 1994). It is common for PLWHA to be in hospital when they are initially referred to the community nursing services and ideally, it is recommended the community nurse meet the client prior to discharge to explain their role (ACHA, 1991).

Discharge planning presents the community nurse with information to assist the nursing diagnosis and development of a care plan (Armitage, 1995; Wright et al., 1993). The successful coordination of the client's discharge also has benefits to the health care team and the health care system (Nazarko, 1998).

Delays in hospital discharge can be stressful to clients and be caused by inadequate community based services and social networks (Widman, Light & Platt, 1994). Other causes include physician, patient, family and community factors, and this was increasingly recognised as a cost and quality management issue (Sharp et al., 1991). Regular outpatient visits for therapies can also be a severe burden to PLWHA, due to the journey

and waiting time. These visits may have a negative effect on their quality of life and may even make readmission to hospital inevitable (Moons, et al., 1994).

Obviously, people live in the community rather than hospitals, and they need adequate local support systems to assist them to maintain maximum independence within their existing social support systems (Moore & Appleby, 1993). Community nurses can forestall hospital admissions and readmissions, decrease the length of stay in hospital and facilitate outpatient and home treatments of clients with HIV/AIDS at a comparatively low cost to hospital based care (Arkell, 1993; Carney, 1990; Schroeder, 1993). Specialised home care significantly decreases the disruption illness causes to the lifestyle of PLWHA (Moons at al., 1994). Due to the negative psychological and physiological effects of frequent hospitalisation on the client, their family and the socioeconomic effect on the health care system, health care providers should advocate the home setting as the preferred environment to provide care to PLWHA (Salyer et al., 1987).

1.4.3 Nursing Knowledge Deficits and Research Needs

The nursing care of clients with HIV/AIDS in any setting has continued to provide challenges (Meeks-Festa et al., 1994) as knowledge deficits related to the treatment, management, and specific nursing care needs of clients with this illness are identified and explored. As the body of knowledge grows, the treatment and the course of HIV/AIDS illness is changed. Rather than a short and fatal illness trajectory, clients often experience alternating periods of acute illness and relative stability (Foley et al., 1995; Sowell, 1995).

As improved treatments have significantly increased the survival time of

PLWHA (Hurley & Ungvarski, 1994; Wright et al., 1993), there is a greater need for nursing knowledge regarding the long term care of these clients (Twyman & Libbus 1994; Ungvarski, 1992). This is particularly true for community nursing, as the need for hospitalisation has decreased and PLWHA are mainly cared for in the community setting (Hurley & Ungvarski; Moore & Appleby, 1993; Salsberry, Nickel & O'Connell, 1991; Schietinger, 1986; Schmidt, 1992). As a result, there has been an increase in requests for community nurses to care for and maintain maximal independence for PLWHA experiencing symptoms at home (Gary, 1991; Hurley & Ungvarski; Layzell & McCarthy, 1993; Ungvarski, Scimmdt & Neville, 1994). The client's complicated psychoemotional and social issues along with the multiple physical manifestations which result from their incompetent immune system, are compounded by longer survival rates; and this presents challenges to community nurses in clinical practice (Hurley & Ungvarski; Ungvarski et al.). In order to provide holistic care to PLWHA, community nurses need to identify needs, determine nursing diagnoses, plan and implement interventions and evaluate outcomes (Salyer et al., 1987).

A primary intent of nursing research is to increase the body of knowledge that identifies needs and determines evidence based nursing practice (Hurley & Ungvarski, 1994; Salyer et al., 1987; Zeller, Swanson & Cohen, 1993). The complicated nature of the clinical, demographic and psychoemotional aspects of PLWHA presents formidable challenges to nursing research (McCain & Zeller, 1994). There is a dearth of literature, particularly from Australia, that identifies information regarding the referral of PLWHA to community nurses and the effect this has on hospitalisation, discharge planning (Armitage, 1995), rehospitalisation, and their ongoing nursing management. Although some overseas data currently exists, there is little Australian literature identifying research-based data describing the nursing needs of PLWHA in the home setting.

This was the case internationally in the mid 1990s (Ungvarski & Hurley), when it was acknowledged the recognition of such needs determines the effectiveness of nursing interventions (Corless, Halloran & Belyea, 1994). A data base of clinical and psychosocial aspects of people with AIDS is essential to identify the home nursing care needs of this group (Ungvarski et al., 1994). More nursing knowledge is required, particularly in the assessment, measurement and management of the important areas of symptom management (Hegyvary, 1993; Holzemer et al, 1999), social support (Langford Bowsher, Maloney & Lillis, 1997; Lawton, 1983), and psychosocial issues (Bennett, Rose, Jackson & Thomas, 1998). In addition, longitudinal studies are required through the erratic disease trajectory, as well as studies to assess the burden of care on caregivers (Foley et al., 1995). Scientific research into the holistic physical, mental, spiritual, and environmental care of clients is vital to the discipline of nursing (Zeller et al., 1993). Community nurses must become more involved in research in order to ensure that quality care is offered (Hurley Hurley & Ungvarski, 1995) through the measuring of patient outcomes, and through the cost effectiveness of their interventions to PLWHA (Hurley & Ungvarski, 1994).

1.5 Study Purpose

The purpose of this retrospective study is to identify, describe and explore the clinical, demographic and psychoemotional aspects of adult clients with advanced HIV/AIDS who were referred to community nursing services between 1993 and 1995. The major findings of the study will be discussed broadly within the context of community nursing practice and recommendations will be made for future community nursing interventions.

1.6 The Research Questions

The following four research questions are explored in this study:

- 1) What are the demographic, clinical and psychoemotional aspects of adult clients experiencing advanced HIV/AIDS documented on Community Nursing Referral Forms (CNRFs)?
- 2) What is the association between the most commonly identified clinical aspects of the clients in the study?
- 3) Are there identifiable key emergent themes from the HIV/AIDS clients' documented psychoemotional status?
- 4) What are the most commonly documented requests made of community nurses on CNRFs for clients diagnosed with advanced HIV/AIDS?

1.7 Study Significance

An understanding of the clients' demographic, clinical and psychoemotional aspects has implications for future nursing practice, education and research (Ungvarski, 1994). Outcomes can be used to formulate standards and guide nurses who are unfamiliar with caring for PLWHA (Holzemer & Henry, 1991; Zeller et al., 1993). A detailed data base of information concerning PLWHA could be developed that, in addition to indicating the client's current status, alerts the nurse to potential problems (Ungvarski et al., 1994). Findings from this study have the potential to promote the early detection and diagnosis of the HIV-related problems of PLWHA with advanced illness referred to community nurses and therefore, facilitate a high standard of care. As there is limited available information regarding community nursing of clients with advanced HIV/AIDS, particularly in Australia, the findings of this descriptive study could also be used as the foundation for higher level studies (Skodal Wilson, 1989).

As community nurses provide leadership in the implementation of home care services (Zeller et al., 1993), their knowledge may assist other home service providers offer a higher standard of effective care. The findings of this study may also be used to enhance the informed client's ability to monitor their own health. This knowledge also has significant positive impacts from an individual, public health and health care service perspective, for example PLWHA may benefit from a feeling of having a greater sense of control over their physical well-being (Stewart et al. 1997).

In summary, it is anticipated that increased knowledge of the demographic, clinical and psychoemotional aspects of the clients referred and the community nursing role may:

- ◆ Assist in the identification of the nursing care needs of this specific group.
- ◆ Lead to an improvement in health delivery systems. For instance a review of the role of community nurses, an improvement to the CNRFs currently used, the development of a networking system with appropriate protection rights for the use of community nurses, review of community nursing assessment forms and other quality improvement strategies.
- ◆ Form the basis for further research. For example, facilitate the comparison of requests documented on CNRFs to nursing interventions documented in community nursing files; a study focussing on a specific identified clinical, demographic or psychosocial aspect of clients referred to community nurses; or comparisons of results to similar studies based in other settings and times (Lucey, Bicknell & Burke, 1998).

1.8 Outline of the Thesis

Chapter 1 provides an introduction to the study, the problem, its justification, purpose, questions and significance.

Chapter 2 reviews the literature that discusses the clinical, demographic and psychoemotional aspects of people living with HIV/AIDS and related community nursing issues.

Chapter 3 describes the research design. This includes the quantitative methods used to collect and analyse the data and the qualitative methods utilised to further explore the psychoemotional status of clients as reported on the CNRFs. In addition, the limitations of the study are identified and the ethical considerations are discussed.

Chapter 4 presents the findings from the analysis of the clinical, demographic and psychoemotional data, as well as the requests made to community nurses.

Chapter 5 discusses the main quantitative and qualitative findings related to study objectives, literature and broad community nursing issues.

Chapter 6 provides the conclusions concerning the findings of the study and describes the broad implications for the care of PLWHA and for community nursing practice. Recommendations are offered for further research in these areas.

1.9 Conclusion to Introduction

A brief background to the study, the research problem, aims and significance of the study has been presented.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

In this chapter an examination of the literature is provided in relation to the key objectives of the study. An overview is provided of the role of the community nurse; the history of the HIV/AIDS pandemic; the classification of HIV disease; Australian HIV/AIDS statistics; and the demographic, clinical and psychoemotional aspects of PLWHA. These aspects are discussed from the perspective of the broad health care needs of PLWHA with a focus on nursing and, in particular, the role of the community nurse.

2.2 Background to Community Nursing

The innovative Australian Community Health Program (Hospital and Health Services Commission, 1973) pre-empted many aspects of the Ottawa Charter for Health Promotion (WHO, 1986) with its emphasis on reorienting health services, strengthening community action for health, creating supportive local environments for health, and encouraging and supporting self help. It was the implementation of this program in 1973 that led to each area health service region being equipped with a multidisciplinary allied health team based at a Community Health Centre (Palmer & Short, 1989). Primary health care strategies have directed health care workers to understand the communities they serve and assist them to effect sustainable change that promotes health (Holzemer, 1992).

The Generalist Community Nurse practises in line with the World Health Organisation's 1974 definition, as part of a team, focussed on broad community health issues within a geographically designated area. He or she has an understanding of their designated area in terms of community populations, cultural and local issues relevant to health, and networks of

community health and support services.

Community nurses encourage and facilitate personal autonomy of individuals within the community, assisting them to make informed choices regarding their health. Interventions based on equitable health service delivery must be flexible to meet the changing needs of individuals, families and the community as a whole (Chalmers et al., 1991). These may include community involvement; community development; intersectoral collaboration; and social, political and professional advocacy (McMurray, 1991). The holistic role of the Generalist Community Nurse involves multidisciplinary teamwork and includes (Rorden & McLennan, 1992):

- ◆ Direct care to those who are unwell at home.
- ◆ Support and education of caregivers.
- ◆ Referral to, coordination of, and liaison with other service providers.

Direct care includes assistance with personal care, therapeutic interventions, palliative care and emotional support.

Due to the broad role of Generalist Community Nurses, they do not usually limit their practice to one nursing specialty. In most NSW Area Health Services the care of clients with HIV/AIDS is mainstreamed, which means the community nurse caring for the client with HIV/AIDS will have a caseload of clients with a wide variety of diagnoses and needs. For the purpose of this study, the term community nurse refers to the Generalist Community Nurse.

2.3 Background to the HIV/AIDS Disease

2.3.1 Historical Background to the HIV/AIDS Pandemic

The alarming incidence of the previously rare conditions of Kaposi's Sarcoma (KS) (Millar, Goldstein & Gelmon, 1997) and pneumocystis carinii pneumonia (PCP) in 1981 in the United States of America (USA) amongst

men who had sexual contact with men, injecting IDUs and blood transfusion recipients led to the epidemiological study of HIV disease (Kaldor & Rubin, 1994). Shortly after, HIV/AIDS was identified within the same community groups in most Western countries (known as Pattern 1 countries), as well as in people of Haitian and African origin where the main mode of transmission was heterosexual contact (known as Pattern 2 countries). Krause (1993) stated that when the major modes of transmission of HIV became apparent in 1982 "...we all knew we were in for a hell of a fight" (p. 357). In Australia, the first case of AIDS was diagnosed in Sydney in 1982 in a man who had previous homosexual contact in the USA. Retrospective analysis of stored sera demonstrated that HIV was present in Australia in 1981 and it was postulated that the virus entered the country some years prior to this time (Kaldor & Rubin). HIV/AIDS has been a notifiable disease in Australia since 1984 (Whyte & Cooper, 1988).

The causative virus (HIV type 1) was discovered in 1983 and serological assays for antibodies to HIV were developed in 1984, allowing diagnosis of HIV infection in symptomatic and non-symptomatic people (Kaldor & Rubin, 1994). Although inconsistencies exist due to under-diagnosis, under-reporting and differences in classification systems over time in addition to delayed reporting, the World Health Organisation (WHO) has recorded the global incidence of reported cases of HIV/AIDS. During the study period from 1993 to 1995, the regions reported to have the highest incidence of HIV/AIDS cases world wide were the Americas (most commonly USA) and Africa, and this remains the case today (Table 2.1). The representation of AIDS cases in Oceania has been low and has continued to decrease over time (WHO, 1999). At the commencement of this study in June 1993, 88% of all AIDS cases reported to the WHO in the Oceania region were from Australia (WHO, 1993). At the end of the study

in June 1995, WHO (1995) estimated that a cumulative total of over 20 million adults and children had contracted HIV infection. (Refer to Section 1.4 for additional global statistics).

Table 2.1 Percentage of Total HIV/AIDS Cases in Adults and Children Reported to the World Health Organisation by Continent and Year.

Continent	1985^a	1993^b	1995^c	1999^d
Africa	4%	34%	36%	40%
Americas	89%	52%	50%	51%
Asia	0.06%	0.5%	2%	7%
Europe	6%	13%	12%	11%
Oceania	0.8%	0.6%	0.6%	0.5%
World Total	27,551	718,894	1,169,811	1,987,217

Note. ^aFigures up to end 1985 (UNAIDS/WHO, cited in AIDS 11(5) 1999 p. 622). ^bFigures up to June (WHO, 1993). ^cFigures up to June (WHO, 1995). ^dFigures up to November (WHO, 1999).

2.3.2 The Human Immunodeficiency Virus

HIV is a retrovirus that is generally acknowledged to be transmitted in three ways: i) through sexual contact, ii) by blood or tissue to blood contact, and iii) from mother to child in utero or by breastfeeding. A retrovirus is a subfamily of viruses which: "...possess a unique enzyme, reverse transcriptase, which copies the viral ribonucleic acid (RNA) into deoxyribonucleic acid (DNA), allowing viral genetic information to be inserted into the host cell chromosomes and replicate with them"

(Cunningham, 1994, p.10). Clinical manifestations of primary HIV infection occur in fifty percent of people following transmission (Gold, Donovan & Penny, 1994). This is described as a ‘mononucleosis like’ illness, which occurs one to six weeks following transmission. It is normally self limiting and antibodies to HIV can usually be found within three to six weeks of the onset of illness (Gold et al.).

HIV infects CD4 T lymphocytes and other cells and has the ability to remain dormant for an unspecified period of time, eventually replicating and killing the host cell. “[T] Cells with the marker CD (cluster designation) 4 provide help to B cells [lymphocytes] in antibody production and induce cell-mediated immunity involving macrophages” (Stewart, 1994, p.18). As the CD4 T-lymphocytes play a vital role in the instigation of a number of important immunological functions, their loss results in progressive impairment of the immune response and the increased risk and severity of opportunistic illnesses (Centres for Disease Control [CDC], 1992).

2.3.3 Classification of HIV Disease

The Centres for Disease Control (CDC) in the USA developed a case definition of HIV/AIDS initially in 1982 which was used world wide to allow standardised reporting of the disease. Despite reporting inconsistencies, it was important that the HIV classification systems remained flexible and were reviewed as knowledge of HIV/AIDS disease increased (Whyte & Cooper, 1988). This original CDC case definition was revised in 1985 and again in 1987, and 1992 (CDC, 1992). Australia adopted the CDC 1992 classification with some modification to the AIDS case definition, as is outlined in Australian National Council on AIDS (ANCA) Bulletin, 1994 (**Appendix A**). This Australian version is used in this study to categorise the identified clinical conditions of the clients into HIV Category C, B or non-B or C conditions.

While giving some indication of immune status, the HIV classification system cannot be used independently to assess the current health status or needs of individual PLWHAs. Some people who experience intermittent or chronic disabling symptoms have not yet been diagnosed with an HIV Category C AIDS-defining illness. Conversely, others who are diagnosed with an HIV Category C illness may subsequently experience a full recovery, enabling them to resume former activities (Bennett, 1988). From a nursing perspective, the HIV classification or medical diagnosis alone will not be useful in assessing the holistic needs of individual clients or determining the nursing diagnoses (Bennett; Schietinger, 1986).

2.4 HIV/AIDS Demographics

An overview of the demographic aspects of PLWHA is presented to provide a background to this part of the first research question, as stated in Section 1.6. As with global statistics, Australian HIV/AIDS statistics are also limited by inconsistencies, mainly due to the duplication of cases and late reporting. The new and cumulative figures for the incidence of HIV infection in 1995 published by the NCHECR in Australia around 1995 are quite different to those published for this same time period in 2000. Discrepancies in statistics for the same period of time are mainly due to the retrospective review and adjustment of the reported incidence in order to address these inconsistencies. Unless otherwise stated, the presented statistical data in this section were current at the time period to which they refer.

2.4.1 The Incidence of HIV Infection, AIDS and Death in Australia and New South Wales in 1993, 1995 and 2000

The reported new and cumulative cases of people in Australia and NSW with HIV infection, AIDS and who died following AIDS within the study period and currently, are presented in Table 2.2. Despite an increased incidence of new cases outside of NSW since the study period, around half of the cumulative figures have continued to be reported from NSW. Compared to the study period of 1993-1995, there has been a significant decrease in the number of people newly diagnosed with HIV infection, AIDS, and who have died following AIDS in 2000. In NSW, there was an estimated 534 people who died following AIDS during the two year study time and this significantly decreased with only 98 people dying following AIDS in the two year period ending June, 2000 (NCHECR, 2000a).

The majority of the presented statistics in Table 2.3 have been adjusted for duplication and reporting delays by the NCHECR since they were first reported. These adjusted figures are reported by calendar year in the 2000 Annual Surveillance Report. On comparison with Table 2.2, the most striking discrepancy is the decrease in cumulative HIV infections, due to the adjustment of duplicated cases since the study period. The other notable comparative change in the adjusted figures was the increase in the 1999 new AIDS cases and the NSW proportion of Australian figures.

Table 2.2 Reported Cases of Total Australian and NSW HIV Infections, AIDS Diagnoses and Deaths Following AIDS During the Study Time in 1993, 1994, 1995 and 2000.

	30th June 1993 ^a		30th June 1994 ^b		30th June 1995 ^c		30th June 2000 ^d	
	New ^e	Cum ^f	New ^e	Cum ^f	New	Cum ^f	New ^e	Cum ^f
HIV Infections								
Australia	1,165	17,475 ^g	990	18,274 ^g	897	19,087 ^g	744	20,599 ^h
NSW	662	11,649 ⁱ	472	11,964 ⁱ	435	12,320 ⁱ	368	11,946 ^j
NSW as % of Australian total	57%	67%	48%	65%	48%	65%	49%	58%
AIDS Cases								
Australia	568	4,258	607	5,075	655	6,035	182	8,422
NSW	288	2,502	323	2,953	334	3,504	91	4,881
NSW as % of Australian total	50%	59%	53%	58%	51%	58%	50%	58%
Deaths Following AIDS								
Australia	471	2,786	548	3,529	563	4,309	95	5,885
NSW	210	1,588	265	2,025	269	2,462	46	3,310
NSW as % of Australian total	45%	57%	48%	57%	48%	57%	48%	56%

Note. ^aNCHECR, 1993b. ^bNCHECR, 1994b. ^cNCHECR, 1995. ^dNCHECR, 2000a. ^eNew = New cases reported in the previous 12 month period.

^fIncludes people whose sex was reported as transgender. ^gIncludes 2090-2095 people whose sex was not reported. ^hIncludes 271 people whose sex was not reported. ⁱIncludes 2028-2048 people whose sex was not reported. ^jIncludes 247 people whose sex was not reported.

Cum = Cumulative.

Table 2.3 Reviewed and Adjusted Reported Cases of Total Australian HIV Infections, AIDS Diagnoses and Deaths Following AIDS for Years of 1993, 1994, 1995 and 1999^a

	1993 ^b		1994 ^b		1995 ^b		1999 ^b	
	New ^c	Cum ^e	New ^c	Cum ^e	New ^c	Cum ^e	New ^c	Cum ^e
Estimated HIV Infections								
Australia	1,017	12,663	928	13,591	872	14,463	679	17,441
NSW	607	7,635	518	8,153	564	8,717	330	10,215
NSW as % of Australian total ^d	60%	60%	56%	60%	65%	60%	49%	59%
AIDS Cases								
Australia	844 ^e	5,059	955 ^e	6,014	805 ^e	6,819	196 ^e	8,362 ^e
NSW	479	2,990	551	3,541	467	4,008	126	4,865
NSW as % of Australian total ^d	57%	59%	58%	59%	58%	59%	64% ^e	58% ^e
Deaths Following AIDS								
Australia	695 ^e	3,453	735	4,188	652 ^e	4,840	112 ^e	5,850 ^e
NSW	367	1,991	405	2,396	341	2,737	59	3,235
NSW as % of Australian total ^d	53%	58%	55%	57%	52%	57%	53%	55%

Note. ^aAll figures adjusted for duplicated cases and/or reporting delays. ^bAustralian Surveillance Report (NCHECR, 2000)^b.
^cNew = New cases reported in the previous 12 month period. ^dFigures estimated by researcher based on presented data. ^eIncludes people whose sex was reported as transgender. Cum = Cumulative

2.4.2 Gender of PLWHA

Like other developed Western countries, the highest proportion of PLWHA in Australia are men (NCHECR, 2000b) (Table 2.4). As a result, most, documentation of the clinical course of HIV infection has been based on the presentation of progression in men. However, Phillips et al. (1994) found little difference in the clinical course of AIDS between the sexes, although women were identified as being at greater risk of toxoplasmosis and Herpes Simplex Virus (HSV) ulceration.

Despite the comparatively lower incidence, like the USA (Rose, 1993; Rose & Clark-Alexander, 1996), the incidence of AIDS in Australia is increasing more rapidly in women than in men. This is due to the escalation of heterosexual HIV transmission, the most common mode of exposure in Australian women (Mijch, Clezy & Furner, 1997). The increase of the proportion of females in Australia and NSW reported to have HIV infection, AIDS or to have died following AIDS, has remained fairly stable since the study time for both cumulative and new cases with a range of 0-6% of all infections. However, there is known to be a higher proportion of infected women in the Aboriginal community (28% of all infections amongst this group) (NCHECR, 2000). The proportion of PLWHA who are transgender has remained stable since the study time at between 0.1- 0.3% of all cumulative Australian HIV infections, AIDS diagnoses and deaths following AIDS (NCHECR, 1994b; NCHECR, 1995; NCHECR, 2000b).

Table 2.4 HIV Infections, AIDS Cases and Deaths in Australia and NSW by Gender During the Study Time, 1993-1995 and 2000.

	30 June 1994 ^a			30 June 1995 ^b			30 June 2000 ^c		
	%m	%f	Total	%m	%f	Total	%m	%f	Total
Australia									
Cum HIV Infections	84	5	18,274	84	5	19,087	92	6	20,599
Cum AIDS Cases	96	4	5,075	96	4	6,035	95	4	8,422
Cum AIDS Deaths	97	3	3,529	96	3	4,309	96	4	5,885
New South Wales									
Cum HIV Infections	79	4	11,964	79	4	12,320	92	5	11,946
New ^{d,e} HIV Infections	94	6	472	91	9	435	92	8	368
Cum AIDS Cases	96	3	2,953	96	3	3,504	96	4	4,881
New ^{d,e} AIDS Cases	97	3	323	96	4	334	88	12	91
Cum AIDS Deaths	96	2	2,025	96	3	2,462	96	3	3,310
New ^{d,e} AIDS Deaths	96	4	265	95	5	269	100	0	46

Note. Transgender clients represented by 0.1-0.2% of Australian cumulative HIV infections and 0.3% of Australian cumulative AIDS cases and deaths following AIDS. Unreported gender not presented. NSW Percentages are approximate. Cumulative totals include transgender ^aNCHECR, 1994b. ^bNCHECR, 1995. ^cNCHECR, 2000a. ^dNew=During the previous 12 month period. ^eFigures estimated by researcher based on presented data. Cum=Cumulative. %m= percentage male. %f = percentage female.

2.4.3 Country of Birth of PLWHA in Australia

From the 78% of people in Australia in 1993 known to have AIDS whose country of birth was reported, 75% were born in Australia, 6% in the United Kingdom (UK) or Ireland, and 4% born in Oceania (Kaldor et al. 1993). This reflects the general distribution of countries of birth in the total Australian population (Australian Bureau of Statistics [ABS], 1996). These figures have remained fairly stable amongst the 2,278 people diagnosed with AIDS between 1995 and 1999, with 73% born in Australia and 27% born overseas. The most common countries of birth were in Europe (5% from the UK and Ireland, 6% from other European countries), and 5% each from Asia and New Zealand. This reflects the increase in the general population of people born in European countries (outside the UK and Ireland) and Asia (NCHECR, 2000b). It appears that the country of birth has no significant impact upon the Australian AIDS epidemic (Kaldor et. al 1993).

2.4.4 Age of PLWHA

When HIV infections are considered, people aged between 20-39 years represent 59-71% of the new and cumulative cases between the study time of 1993-1995 and for 2000 (Table 2.5). When people with AIDS and deaths following AIDS are considered, those aged between 30-49 years represent between 69-74% and 71-80% respectively of the new and cumulative cases during the study time and for 2000. Compared to the deaths following AIDS during the study time, there has been a 7% increase in the proportion of people aged 30-39 years and a 4% decrease in those aged 40-49 years in 2000. Despite these trends, the most common age at HIV infection, AIDS diagnosis and death following AIDS has remained stable at 30-39 years of age.

Table 2.5 HIV Infections, AIDS Cases and Deaths in Australia by Age During the Study Time, 1993-1995 and 2000.

Age Group	30 June 1994 ^a		30 June 1995 ^a		30 June 2000	
	New ^{d,e}	Cum ^f	New ^{d,e}	Cum ^f	New ^{d,e}	Cum ^f
HIV Infections						
20-29yrs	35%	30%	32%	30%	25%	35%
30-39yrs	36%	29%	38%	29%	43%	36%
40-49yrs	14%	13%	16%	13%	18%	17%
50-59yrs	7%	4%	6%	4%	8%	6%
Unknown	1%	22%	0.4%	21%	1%	1%
Other	7%	2%	8%	3%	5%	5%
Total	990	18,274	897	19,087	744	20,599
AIDS Cases						
20-29years	15%	19%	14%	18%	8%	17%
30-39years	44%	41%	47%	42%	47%	42%
40-49years	30%	28%	27%	28%	24%	27%
50-59years	9%	9%	7%	9%	15%	10%
Other	2%	3%	5%	3%	6%	4%
Total	607	5075	655	6,035	182	8,422
Deaths Following AIDS						
20-29years	8%	14%	7%	13%	6%	12%
30-39years	41%	40%	44%	40%	48%	40%
40-49years	36%	31%	32%	31%	32%	31%
50-59years	10%	11%	12%	11%	11%	12%
Other	5%	4%	5%	5%	3%	5%
Total	548	3,529	563	4,309	95	5,,885

Note. All percentages are approximate. ^aNCHECR, 1994b. ^bNCHECR, 1995. ^cNCHECR, 2000a. ^dNew = New cases reported in the previous 12 month period. ^eFigures estimated by researcher based on presented data. ^fIncludes people whose sex was reported as transgender. Cum = Cumulative.

2.4.5 Exposure Categories of PLWHA

Globally in 1993, heterosexual transmission was the exposure category for 90% of women and 60% of men infected with HIV, and this proportion was expected to rise (Mann, 1993). As a pattern 1 country (Section 2.3.1), around 90% of diagnosed AIDS cases in Australia have occurred in men who have a history of homosexual contact (Kaldor & Rubin, 1994). HIV transmission in Australia is also attributed to the receipt of blood products and tissue, and transmission from mother to newborn (Kaldor et al., 1993). Although these most common exposure categories have not changed since the study time, there has been a decrease in the proportion of homosexual and bisexual transmissions and an increase in heterosexual transmissions of HIV from 1992 to 1999. Aboriginal people have a higher rate of heterosexual transmission of HIV compared to the general population (36% versus 15%) (NCHECR, 2000b).

Up to June 1995, the cumulative total of reported deaths following AIDS In Australia was 4,309, with the most common exposure category by far being male homosexual/bisexual contact (84%) (Table 2.6). However, when the exposure categories of the deaths which occurred in the twelve months prior to the end of June 1994 ($n = 548$) and 2000 ($n = 95$) are compared, there is a significant decrease in homosexual contact (83% to 66%) and a significant increase in heterosexual contact (6% to 14%). Therefore, preventative interventions need to target not only men who have sex with men, but the heterosexual community as well.

Table 2.6 Deaths Following AIDS in Australia by Exposure Category During the Study Time, 1993 - 1995 and 2000

Exposure Category	30 June 1994^a		30 June 1995^b		30 June 2000^c	
	new^{d,e}	cum^f	new^{d,e}	cum^f	new^{d,e}	cum^f
Male Homo/Bi sexual Contact	83%	85%	79%	84%	66%	84%
Male Homo/Bi sexual Contact and IDU	4%	3%	5%	4%	6%	4%
IDU (female and heterosexual male)	2%	2%	4%	2%	3%	3%
Heterosexual Contact	6%	3%	5%	3%	14%	4%
Haemophilia/Coagulation Disorder	1%	1%	1%	1%	2%	2%
Receipt of Blood/Tissue	1%	3%	1%	3%	0%	2%
Health Care Setting	NS ⁱ	NS ⁱ	0%	0%	0%	0%
Total Children ^g	0.7%	0.7%	0.7%	0.7%	0%	0.6%
Other/ Undetermined	2%	3%	3%	3%	8%	3% ^h
Total	548	3,529	563	4,309	95	5,885

Note. All percentages are approximate ^aNCHECR, 1994 ^bNCHECR, 1995 ^cNCHECR, 2000 ^a ^dNew = New cases reported in the previous 12 month period ^eFigures estimated by researcher based on presented data. ^fIncludes transgender PLWHA. ^gChildren = Aged 13 years or under. ^hIncludes 17 transgender PLWHA. Cum = Cumulative. IDU = Injecting Drug Use. NS = Not Stated.

2.5 Clinical Aspects of PLWHA

An overview of the clinical aspects of PLWHA is presented to provide a background to this part of the first research question and the second question, as stated in Section 1.6. Assessment of the clinical aspects of clients, for example diagnoses and symptoms, will assist to determine their community nursing needs.

2.5.1 HIV/AIDS Disease

2.5.1.1 Progression of HIV Disease

The fall in the CD4 T lymphocyte cell count is the most characteristic feature of progression of HIV illness (Gold et al., 1994) as it reflects the client's immunocompetence. It is the most efficient indicator of the client's vulnerability to HIV-related clinical conditions as well as their prophylactic therapy needs (Dwyer, Adelstein, Cunningham, Dowton & Merigan, 1997). Normal range for CD4 count varies between laboratories, however above 500 cells/mm³ maintains immunocompetence (Sutherland, 1994) and this represents the first of three generally recognised broad ranges in adults.

Intermediate immune deficiency is defined by a CD4 cell count between 500 and 200 cells/mm³. This stage lasts, on average around 5 years (Adelstein, McKnight & Pethebridge, 1997). Frequent cutaneous and mucosal conditions which commonly occur during this stage include seborrhoeic dermatitis, tinea, molluscum contagiosum and other minor skin disorders, bacterial folliculitis, warts, gingivitis, chronic sinusitis, herpes zoster, oral hairy leukoplakia and oral and vaginal candidiasis. The AIDS-defining illnesses of KS and Non-Hodgkins Lymphoma (NHL) may also appear at this stage, or more uncommonly, HIV encephalopathy. Furthermore, the AIDS-related Complex (ARC) of unexplained weight loss, fever and diarrhoea may also occur late in this phase (Adelstein et al.; Sutherland, 1994). The presentation of these clinical conditions can cause

the client to experience psychological crises, as they herald a declining CD4 cell count and disease progression.

Advanced immune deficiency is defined as a CD4 cell count below 200 cells/mm³. During this stage the immune system is unable to regenerate, leading to severe immunodeficiency and systemic opportunistic infections (Marriott & McMurchie, 1997). However, the initiation of successful antiretroviral therapy will increase the CD4 count (Saag et al., 1996). It is at this stage prophylaxis for PCP is indicated (Sutherland, 1994). Most people who enter this phase are relatively healthy and able to recover from their initial and even subsequent AIDS-defining opportunistic infection. However, they eventually deteriorate, becoming debilitated and losing their physical ability and function, and for some, their cognitive abilities (Marriott & McMurchie). The prognosis worsens as the CD4 cell count declines, with the greatest risk of death for those with a CD4 count of less than 50 (De Gruttola, Wulfsohn, Fischl & Tsiatis, 1993).

The CD4 count alone is inadequate in assessing HIV progression and response to antiretroviral therapy. Its decline is caused by viral replication and this also needs to be monitored using plasma HIV RNA determinations (Saag et al., 1996). The maintenance of plasma RNA levels below 10,000/ml is associated with a decreased risk of progression from HIV infection to AIDS, and lower levels generally correlate with an increased CD4 count in clients whose antiretroviral therapy is effective (Saag et al.). Antiretroviral therapies inhibit HIV replication and, with over ten agents available, combination therapy is known to be more effective than monotherapy (Lewin, Crowe, Chambers & Cooper, 1997). Additionally, it has been observed that there are other factors at play as some long term survivors did not participate in the new therapeutic regimes (Stanley, 1994). In Australia, the median survival times of all adults and adolescents reported to have AIDS increased from 17 months in 1993 (a

similar finding to a European study by Phillips et al., 1994) to 32 months in 1997, with survival at two years increasing from 37% to 54% respectively (NCHECR, 2000b).

HIV illnesses may develop slowly or suddenly (Schietinger, 1986) and the course of HIV disease is chronic, complex and leads to multi-system insult and failure (Bennett, 1988; Ungvarski, 1994). The person with HIV/AIDS usually has multiple and coexisting health problems. It is rare for a diagnosis of only one condition to occur (Ungvarski). Most of the causative organisms of opportunistic infections are common, and in many cases will present as a reactivation due to an incompetent immune system rather than a primary infection (Ungvarski et al., 1994). With the advancements in the medical management of HIV, people are surviving infections that were once fatal, only to develop a number of other HIV-related problems (Gary, 1991). Brettle, Foreman and Povey (1996) stated that clients with AIDS can be expected to develop one to two AIDS-related conditions for each year of survival.

Factors identified as possibly associated with increased clinical disease progression from HIV infection to AIDS includes acquiring HIV at 40 years of age or more and continued male homosexual activity (Carre et al., 1994). Other identified factors include a lower CD4 count; male gender; HIV transmission categories other than men who have sex with men (MSWM); diagnosis of an initial AIDS condition; diagnosis of a subsequent AIDS condition; the diagnoses of wasting syndrome, mycobacterium avium complex (MAC), lymphoma, PCP, KS, cryptococcosis, oesophageal candidiasis, tuberculosis, hairy leukoplakia and pneumonia; race and calendar year (Hanson, Horsburgh, Fann, Havlik & Thompson, 1993).

2.5.1.2 The Incidence of HIV - Related Illnesses

In a retrospective chart review of 244 clients with HIV/AIDS in 1991 who

had been referred to a community nursing service in New York, USA, the principal diagnosis on admission was AIDS (89%). The most common AIDS-defining illness documented as a secondary diagnosis was PCP (44%) followed by HIV encephalopathy (15%), HIV wasting disease (14%) and MAC (11%). Other HIV-related conditions frequently documented included anaemia (21%), oral candidiasis (19%), pulmonary tuberculosis (15%), and pneumonia other than PCP (13%) (Hurley & Ungvarski, 1994).

Between 1982-1991 in Australia, a trend was identified of a decreasing proportion of PCP and/or KS as an AIDS-defining illness accompanied by increasing proportions of oesophageal candidiasis, HIV encephalopathy, atypical mycobacteriosis, HIV wasting disease and cytomegalovirus (CMV) disease (NCHECR, 1993a). This trend was also observed in Canada, and it was predicted that the spectrum of AIDS-defining conditions would vary over time (Arkell, 1993; Montaner et al., 1994).

In Australia during the study period (June 1993-June 1995), PCP and/or KS followed by oesophageal candidiasis continued to represent the most commonly occurring cumulative and new AIDS-defining conditions and this has remained the case to the end of 1999 (Table 2.7). Since the study period, there has been an increase in the incidence of new cases of PCP, despite a lower proportion of the cumulative total. This indicates that there has been a decrease and subsequent increase in the incidence of new cases of PCP as an AIDS-defining condition since the study period. This is possibly due to the lack of clinical monitoring and prophylactic treatments because of the more recent increase in late diagnoses of new HIV infections (Section 1.4.1). There has been a decrease in the incidence of KS and oesophageal candida as an AIDS-defining illness and an increase in PCP and other excluding KS. The remaining changes of note include a decrease in the new cases of MAC and CMV and an increase in the new cases of HIV encephalopathy and HIV wasting disease.

Table 2.7 AIDS Cases by AIDS-defining Condition During the Study Time, 1993-1995 and 1997-1999

AIDS-defining Condition	30 June 1994 ^a		30 June 1995 ^b		1997-1999 ^c	
	new ^{d,e}	cum ^f	new ^{d,e}	cum ^f	new ^{d,e}	cum ^f
PCP	25%	33%	20%	30%	24%	28%
KS (skin)	13%	14%	11%	13%	9%	12%
PCP and Other	4%	7%	3%	7%	8%	6%
Oesophageal Candida	14%	8%	14%	9%	9%	10%
Cryptococcus	0%	2%	5%	4%	5%	4%
NHL	4%	3%	4%	4%	6%	4%
MAC	5%	4%	7%	5%	3%	5%
HSV	2%	3%	2%	3%	2%	2%
HIV Encephalopathy	4%	3%	5%	3%	6%	4%
Cytomegalovirus	7%	4%	5%	4%	2%	4%
HIV Wasting Disease	6%	4%	7%	4%	10%	5%
Other	16%	15%	17%	14%	16%	16%
Total	607	5,075	655	6,305	815	8,292

Note. All percentages are approximate. ^aNCHECR, 1994b. ^bNCHECR, 1995. ^cNCHECR, 2000b. ^dNew = New cases reported in the previous 12 month period. ^eFigures estimated by researcher based on presented data. ^fIncludes people whose sex was reported as transgender. Cum = Cumulative. PCP = Pneumocystis Carinii Pneumonia. KS = Kaposi's Sarcoma. NHL = Non-Hodgkins Lymphoma. MAC = Mycobacterium Avium Complex. ^hHSV = Herpes Simplex Virus.

2.5.1.3 Gastrointestinal Disease

Manifestations of the gastrointestinal tract, biliary tree and liver are a major source of illness and death in PLWHA (Sievert, Shaw & Edwards, 1997). Multiple organisms may be involved concurrently with a broad spectrum of signs and symptoms. It is imperative to diagnose the cause of any alteration to normal function and commence the appropriate therapy. Causes of gastrointestinal symptoms (for example, abdominal pain, dysphagia, diarrhoea, gastrointestinal bleeding, jaundice and

hepatomegaly) may be related to an underlying opportunistic infection, AIDS-related neoplasia, adverse reactions to therapeutic medications or the effect of HIV infection alone. Relapse frequently follows treatment (for example, CMV, MAC, cryptosporidia and microsporidia) resulting in the client experiencing weight loss and decreased functional ability (Sievert et al.).

Oral disease is common in HIV patients (Allworth & Bowden, 1997) with xerostomia leading to dental deterioration probably the most significant, and 70% of clients with KS will have lesions in and around their mouth (Foltyn & Marriott, 1997). The most common cause of pain in the oral cavity is oropharyngeal candidiasis (O'Neill & Sherrard, 1993). Recurrent oral ulcers are common and may be aphthous or caused by CMV, Epstein-Barr Virus (EBV) or HSV (Foltyn & Marriott; O'Neill & Sherrard).

Oesophageal disease occurs in about 40% of clients with AIDS with the most common symptoms being dysphagia and odynophagia, and the most common cause being oesophageal candida (Sievert et al., 1997). Other causes of oesophageal disease include CMV, HSV, MAC, idiopathic ulcer and KS (Ehrenpreis & Bober, 1996; O'Neill & Sherrard, 1993; Sievert et al.). Many causes of oesophageal symptoms are treatable, although nearly all clients who are successfully treated for oesophageal candida will experience a recurrence within several months (O'Neill & Sherrard).

Diarrhoea and/or abdominal cramps are common symptoms of gastrointestinal disease in PLWHA. Causative organisms may include cryptosporidia, Shigella, Salmonella, Campylobacter, CMV and Mycobacterium Avium (Allworth & Bowden, 1997; Glare, 1994; Lubeck, Bennett, Mazonson, Fifer & Fries, 1993; O'Neill & Sherrard, 1993; Penfold & Clark 1992; Sievert et al., 1997). Diarrhoea recurs commonly and complications that may arise from chronic diarrhoea include electrolyte

imbalance (Schietinger, 1986) and malnutrition, which can reduce the quality and length of life (Sievert et al.).

CMV infection is a major cause of morbidity in PLWHA. The usual treatment of persistent CMV has involved the insertion of a long term venous access device (LTVAD) and intravenous (IV) administration of the poorly tolerated medications, ganciclovir and/or foscarnet. A continued maintenance regime is often required for systemic CMV. Treatment is often burdensome for the client and reduced quality of life is common (Fisher & Barton, 1996).

Most mycobacterial infections in clients with HIV/AIDS in developed countries are caused by *Mycobacterium Avium*, with an incidence of up to 35% in Australian PLWHA who are severely immunocompromised (Hoy, et al., 1997). Clients with MAC commonly experience non-specific symptoms and signs such as nightsweats, fever, weight loss, anorexia, diarrhoea, abdominal pain and anaemia (Smith & Pigott, 1997; Hoy et al.). The incidence of MAC can be reduced with prophylactic drug therapy offered to PLWHA with a CD4 count less than 50 cells/mm³. It is possible to effectively treat the infection with resultant improved quality of life and lengthened survival (Hoy et al.).

KS may involve the small or large bowel in about half of clients with cutaneous involvement and about 10% may also have liver involvement but this is mostly asymptomatic (Sievert et al., 1997). Clients with GIT lymphomas often present with abdominal pain, gastrointestinal (GIT) bleeding and obstruction. The most common type found in advanced HIV disease is a high grade B cell lymphoma. The liver may be affected in 10-15% of clients and the prognosis is poor with a median survival rate of 6 months (Sievert et al.).

Hepatomegaly is the most common alteration affecting the liver, with MAC being the most common cause resulting in clients with high fever and severe abdominal pain. Other infections affecting the liver include CMV and cryptococcosis. Hepatitis B and particularly C may lead to a form of chronic hepatitis which may be exacerbated by the client having an incompetent immune system (Pritchard-Jones, 1999). Significantly abnormal liver function tests may also be caused by adverse reactions of medications (Sievert et al., 1997).

The most common opportunistic infections affecting the gall bladder and biliary tree are cryptosporidium and CMV. Disease of the anus and/or rectum, including anal fistulas, anal ulcers secondary to infection with HSV and CMV, non-specific idiopathic ulceration, lymphoma and squamous cell carcinoma, occurs frequently in homosexual men (Sievert et al., 1997).

The cause of HIV wasting syndrome is usually multi-factorial and may occur without a significant change in eating habits. Causes of weight loss include systemic disease, malignancy, gastrointestinal disease, malabsorption, decreased oral intake and neuropsychiatric abnormalities. Some specific causes include MAC, CMV, NHL, cryptosporidia, microsporidia, *Candida Albicans*, HSV, KS, anorexia, medication, depression, dementia, confusional states, fear that food will exacerbate diarrhoea, poor functional abilities (for example, food preparation), HIV enteropathy, pancreatic insufficiency and small-bowel dysfunction (Kelly, Lloyd & Kemp, 1997).

2.5.1.4 Respiratory Disease

Respiratory illnesses will effect up to two thirds of PLWHA, many of which are treatable and some preventable (Smith & Pigott, 1997). The symptoms of PCP include a non-productive cough, sweats, dyspnoea and fever, while

bacterial chest infections are associated with an abrupt onset of fever, productive cough, dyspnoea and possibly chest pain (Smith & Pigott). *Streptococcus Pneumoniae* is the most frequent cause of bacterial pneumonia and bacterial bronchitis is also common, particularly in smokers (Allworth & Bowden, 1997). Following an episode of PCP, all clients should take medication to prevent a recurrence. HIV infection represents the greatest risk factor for the development of active tuberculosis and the infection can be rapid when the immune system is incompetent.

2.5.1.5 Integumentary Disease in PLWHA

Skin problems are frequent in PLWHA and can cause physical and psychological discomfort (Bennett, 1988). Of the many skin disorders that PLWHA may develop, infections are the most common (Wong & Shumack, 1997) and they tend to worsen as immunodeficiency progresses, with recurrence and resistance to treatment common. This is the case for the common viral infections of HSV and molluscum contagiosum (caused by a poxvirus). HSV may lead to secondary infection, chronic ulceration or pain. Herpes Zoster infection may cause pain, skin lesions and vasculitis and, in more severe immunodeficiency, may disseminate to affect more than one dermatome and involve the central nervous system (Foltyn & Marriott, 1997).

Candidiasis affects all PLWHA at some stage and 85 - 95% of clients with HIV disease will develop seborrhoeic dermatitis, which often can be effectively managed with antifungal cream (Wong & Shumack, 1997). Psoriasis may also be severe in clients with HIV disease (Bennett, 1988). Allergic reactions, particularly to medication may also cause dermatological symptoms in PLWHA (Gold et al., 1994).

2.5.1.6 Haematological Disease in PLWHA

Cytopenias are commonly experienced by PLWHA (Ownby, 1995) with symptoms and/or signs of anaemia, neutropenia or thrombocytopenia possible throughout any stage of the infection (McCluskey, Hall & Lightman, 1997). The causes are multi-factorial and potentially life threatening and include treatment-induced cytopenias, malignancies, opportunistic infections, and HIV itself (Ownby). Specific conditions which may lead to cytopenias include MAC (the most common infectious cause); CMV; marrow infiltration by malignancies such as lymphoma and KS; in addition to medications such as zidovudine (Street & Gibson, 1997). A falling CD4 cell count and progression of HIV disease can be reflected in the severity of the anaemia and neutropenia, although this is not the case for thrombocytopenia. Anaemia is the most common cytopenia, occurring in up to 80% of all clients, with fatigue being a common symptom (Street & Gibson).

2.5.1.7 Malignancy in PLWHA

As the management of other manifestations of HIV disease improves, malignancy will increase in incidence as a cause of mortality in PLWHA (Boyle, Goldstein, Frazer & Sculley, 1997). KS, NHL and cervical carcinoma are currently linked to HIV infection, with KS being the most frequent in Australia (Milliken, Clezy, Cooper & Romeril, 1997), and the AIDS-defining illness in 12% of Australian AIDS cases (Boyle et al.).

KS occurs mainly in men and has been linked to a sexually transmissible herpes virus (Boyle et al., 1997). The skin lesions appear as red, purplish or brown coloured macules, nodules or plaques (Millar et al., 1997; Wong & Shumack, 1997) and can cause anxiety, pain, oedema, ulceration and infection. Visceral involvement can affect the lung (10%) resulting in dyspnoea and haemoptysis or the GIT causing blood loss and abdominal

pain. Current treatments are not curative but can reduce the cosmetic disfiguration and visceral complications (Millar et al.).

Unlike KS, lymphoma occurs in all risk groups for HIV infection, although it is more common in the client who is immunosuppressed and has been linked to EBV. NHLs are aggressive and require immediate attention. Symptoms may include fever, nightsweats, weight loss, lymphadenopathy, splenomegaly, pancytopenia, gastric ulcer, hypercalcaemia and masses (Milliken et al., 1997).

2.5.1.8 Neurological Disease in PLWHA

As HIV appears to enter the cerebrospinal fluid soon after initial contact (Brew, Wesselingh, Gonzales, Heyes & Price, 1997), neurological disorders are common and can occur at any stage of the illness (Wright, Brew, Currie & McArthur, 1997). Neurological disorders associated with HIV include encephalopathy, myelopathy, myelitis, peripheral neuropathy, myopathy, cerebral toxoplasmosis, cryptococcal meningitis, syphilis and progressive multifocal leukoencephalopathy; and may involve the cranial nerves. The resultant signs and symptoms include headache, seizure, dementia, fever, nausea, vomiting, altered consciousness, cognitive deficit, psychiatric disorder, reduced mobility, falls, impaired vision, nystagmus, photophobia, facial paresis, vertigo, hearing impairment, dysphagia, dysarthria, sensory changes, paraparesis and loss of sphincter control (Brew et al.; Gary, 1991; Jones, Beaman & Brew, 1997; Schietinger, 1986; Wright et al., 1997).

Peripheral neuropathy is the most common HIV-related neuropathy (O'Neill & Sherrard, 1993) affecting around 45% of PLWHA. It is believed to be caused by direct infiltration of HIV into the nerves (Brew et al., 1997), although the HIV medications didanosine, zalcitabine and stavudine also lead to an identical peripheral neuropathy in 10-20% of clients (Wright et al., 1997). Pain in the soles of the feet is the main symptom for 60% of

those affected (O'Neill & Sherrard), and may be difficult to relieve (Schietinger, 1986). The changing characteristics of the pain should be monitored to determine the appropriate medication to reduce the likelihood of it becoming intractable (Gary, 1991). Clients with severe neuropathy commonly develop a depression that requires treatment (Wright et al.).

At least 20% of PLWHA with advanced immunodeficiency develop HIV encephalopathy and may present with AIDS Dementia Complex (ADC), which is a subcortical dementia (Bennett, 1988; Brew et al., 1997). Symptoms arise from cognitive and motor deficits and include poor concentration, impaired short term memory, slowing of thought processes, confusion, psychomotor slowing, disturbance of motor coordination and gait and behavioural disturbances including social apathy and withdrawal (Bennett; Brew et al.; Wright et al., 1997). The incidence of ADC is increasing, resulting in greater needs of clients with HIV/AIDS, particularly in the areas of activities of daily living and financial management (Schmidt, 1992).

Early signs of cognitive deficit may not be volunteered by clients and are often overlooked, as caregivers such as nurses or family members, may attribute personality changes, apathy or withdrawal to anxiety or depression (Bennett, 1988). In a retrospective chart review of 244 clients with HIV/AIDS discharged from a community nursing service in 1991 in New York (Hurley & Ungvarski, 1994), 15% were diagnosed with HIV encephalopathy on admission. The community nurse, however, identified a memory deficit at the time of admission in 34% of the sample. This supports the value of the community nurse in detecting early cognitive changes due to the amount of time they spend with their clients.

Toxoplasmic encephalitis is the most common cause of focal cerebral lesions in clients with HIV/AIDS (Jones et al., 1997). The causative

organism is *Toxoplasma gondii*, a protozoan found naturally in cats and excreted in faeces for 10-15 days following acute infection and surviving for up to 17 months outside the body (Lander & Reid, 1991). It is important that community nurses educate their clients of the risks involved, and the safe management and handling of cats and their waste materials. However, most cases arise as a result of the reactivation of a previous exposure. Primary prophylaxis may be offered to clients with a CD4 cell count less than 200 cells/mm³ (Jones et al.).

Cryptococcal meningitis is a fungal infection usually heralded by an insidious onset of headache, recurrent fever, and neck stiffness (O'Neill & Sherrard, 1993), with signs of meningism, including neck stiffness, occurring in less than 40% of clients (Jones et al., 1997). Clients should be reassured that most headaches resolve within several weeks (Wright et al., 1997). Clients may present with confusion, impaired level of consciousness, convulsions and focal neurological signs, although these symptoms are less frequent and indicate advanced stages of the illness or the presence of complications such as hydrocephalus (Jones et al.; O'Neill and Sherrard).

PLWHA who have a history of syphilis are at risk of relapsing and developing neurosyphilis. Asymptomatic neurosyphilis is more common in these clients with HIV and may occur despite previous treatment (Jones et al., 1997).

2.5.1.9 Eye Disease in PLWHA

CMV retinopathy is a painless, necrotising infection that destroys the retina (Bennett, 1988). It represents the most serious threat to vision, affecting up to 40% of people with AIDS, who may present with a visual disturbance or asymptomatic lesions only detected by screening. The course of the illness is slow but progressive. Relapse eventually occurs in

most clients despite treatment due to reduced medication dosage because of toxicity or resistance. Clients with a CD4 cell count of less than 50 cells/mm³ or with CMV diagnosed in other sites should be examined every 3 to 4 months by an ophthalmologist to exclude asymptomatic CMV retinitis (McCluskey et al. 1997). Intravitreal ganciclovir may be used for progressive disease (Jones & Loewenthal, 1994).

2.5.1.10 Bacterial Infections in PLWHA

Clients with HIV have a high risk of developing bacterial infections that often recur following therapy, requiring a long-term maintenance regime. Bacterial infections may be attributed to lifestyle, age or treatment, for example sexual behaviour, injecting drug use (IDU), childhood illnesses, medication induced neutropenia or infection of IV lines (Allworth & Bowden, 1997).

One of the most common sites of bacterial infection is the respiratory tract with an increased incidence of otitis media, sinusitis and pneumonia. Headache is a common symptom of sinusitis. Infected LTVADs are often due to staphylococcal infections. Virulent strains found in institutional settings may require its removal.

2.5.1.11 Musculoskeletal Disease in PLWHA

The joints, bone or muscle of clients with HIV may be infected with conventional or atypical bacteria, fungi or other opportunistic organisms. Clinical manifestations include septic arthritis, osteomyelitis, pyomyositis, complete or incomplete Reiters syndrome and psoriatic arthritis (Bertouch, 1997; O'Neill & Sherrard, 1993; Penfold & Clark, 1992). Arthralgias are often very severe and persistent with clients developing erosions and deformities. Diarrhoea commonly precedes a reactive arthritis and generally, there is a high clinical correlation between skin and joint involvement (O'Neill & Sherrard). Musculoskeletal disease in

clients with HIV infection may also be unrelated to HIV. Prompt diagnosis usually results in effective therapy that can often be easily managed with simple medications in the community setting. Pain management is an important aspect of the treatment of musculoskeletal disease and severe cases may require rehabilitation and specialist pain services (Bertouch).

2.5.1.12 Other Physical Clinical Conditions

Cardiac abnormalities are significantly more common in clients with HIV than in the general population, but are often minor and subclinical (Feneley, 1997; Fong, Howard, Elzawi, Simbul & Chiasson, 1993). Feneley postulated that an increase in symptomatic cardiac disease would result from advances in treatment that prolongs the lives of clients with HIV. Abnormalities in renal function and the fluid and electrolyte balance may complicate hospitalisation in 20% of clients. Most HIV-related causes follow opportunistic infection or drug nephrotoxicity (Frankum & Savdie, 1997).

The control of sexually transmissible diseases (STDs) is a major aspect in the overall prevention and management of HIV disease. The STD's usual course may be affected by HIV (for example, HSV and syphilis), and its presence may lead to the progression of HIV disease. Examples of these are KS, B-cell lymphoma and carcinoma of the cervix which are caused by sexually transmissible organisms (Plummer & Furner, 1997).

2.5.2 Psychiatric Disorders in PLWHA

Psychiatric and neuropsychiatric disorders occur commonly in people infected with HIV (Catalan, 1995; Glare & Cooney, 1997; O'Dowd, 1995), particularly depression and anxiety (Buhrich & Judd, 1997). The cause may be organic due to opportunistic infection, malignancy, the direct neuropathic effect of HIV on the brain, iatrogenic and/or psychological due to the personal and social stress related to HIV infection and/or personal vulnerability (Buhrich & Judd; Catalan; O'Dowd).

Furthermore, psychiatric problems have been experienced by many people prior to their HIV infection and the resultant behavioural effects such as depression, intoxication, mania and schizophrenia may have contributed to the exposure of the affected person to HIV (Miller & Riccio, 1990). These effects upon behaviour may include lack of regard for personal safety, apathy, impulsivity and disinhibition, recklessness, substance use, increased sexual activity and poor planning and judgment (Buhrich & Judd, 1997; O'Dowd, 1995).

2.5.2.1 Depression in PLWHA

Depression, as a frequent response to physical illness, is the most common reason for the referral of clients within a general hospital setting for psychiatric assessment (Judd & Mijch, 1994). Along with dementia, depressive symptoms are more commonly reported by PLWHA than in non-HIV clients (Grassi, Pavanati, Bedetti & Bicocchi, 1995).

Assessment of depression is important, but may be difficult to distinguish in its major form from dementia amongst people with advanced HIV illness (Glare, 1994) as well as from the many other causes of the commonly found cognitive and somatic symptoms (Buhrich & Judd, 1997). Determining the level of cognitive function is important in the assessment of depressive symptoms (Mierlak et al., 1995). Depressive symptoms are reactive and

transient and depressive illness lasts over a week. Organic causes should be considered in the absence of predisposing or obvious precipitating factors; in atypical presentations; where cognitive deficit is apparent; and in all those with severe immunodeficiency (Buhrich & Judd).

Other considerations on assessment include medications (for example, corticosteroids may cause depression), ascertaining objective and subjective perceptions (for example, clients with dementia do not complain of feeling depressed although they may appear to be to their carers), the degree of functional impairment (to determine the severity of depressive symptoms) and the risk of self harm due to neglect or suicide (Buhrich & Judd, 1997).

Research is required to establish the coexistence and relationship between subtle neuropsychological impairment, cognitive deficit and depression in PLWHA (Judd & Mijch, 1994; Mierlak et al., 1995). It is vital that that investigations into depression incorporate the aspects of the stage of HIV illness the client is experiencing, the range of symptoms, concurrent cognitive deficit and the outcome of interventions (Judd & Mijch).

2.5.2.2 Other Psychiatric Conditions of PLWHA

Psychosis may occur in PLWHA as a result of relapse of a premorbid condition, drugs (for example, corticosteroids, amphetamines, anabolic steroids, marijuana), metabolic disturbance, infections, the direct effect of HIV on the brain or in rare cases a cerebral lesion (Buhrich & Judd, 1997; Glare, 1994). Symptoms include “elevated mood, disinhibition, insomnia, spending excessively, grandiose or paranoid delusions and occasionally formal thought disorder” (Buhrich & Judd, p 86). Acute psychosis may imitate other conditions such as mania, depression or schizophrenia (Glare). The management of psychosis is determined by the cause (Buhrich & Judd), and those that are responsive to interventions should be

diagnosed early and treated aggressively to maintain dignity and personal safety (Glare).

Suicide occurs more frequently amongst PLWHA than in the general population. Attempts may lead to serious physical harm or death (Grimes & Grimes, 1995). The most accurate way to determine the risk of suicide is through an interview between the health care worker and the client (Valente & Saunders, 1994).

Personality disorder is described under the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) (American Psychiatric Association [APA], 1994) as including clients with a major depression, dysthymic disorder, anxiety disorder, eating disorder, alcohol dependence or drug dependence. A control study by Perkins, Davidson, Leserman, Liao and Evans (1993) found that personality disorder was common amongst PLWHA, with the most common principal diagnosis being borderline personality disorder.

2.5.3 Signs and Symptoms of PLWHA

The presentation of the wide range of signs and symptoms experienced by PLWHA varies. They may be severe and acute, mild and chronic, or have a gradual onset with a progressive course (Schietinger, 1986). The causes of symptoms may be due to the disease process, treatment (Ropka, 1994), depression or may be unrelated to HIV/AIDS (Bennett, 1988; Glare, 1994). It is important that PLWHA are aware of the specific symptoms to which they are vulnerable and how they manifest, in order to assist them monitor their health status and enable early assessment, detection and intervention for new conditions (Stewart et al. 1997).

Henry, Holzemer and Reilly (1994) identified the top five symptoms in their sample of hospitalised PLWHA as dyspnoea, fever, fatigue,

nutritional problems and medication side effects. The symptoms of pain, fatigue/lethargy, weakness, neurological symptoms, dyspnoea, cough, diarrhoea and visual impairment in PLWHA were among the most commonly identified in two studies, one American (n=244) and the other, Australian (n=87) (Glare, 1994; Hurley & Ungvarski, 1994). Other common symptoms included ataxia, skin lesions, nocturia, oral lesions, weight loss (Hurley & Ungvarski), anxiety, depression, anorexia, nausea, vomiting, fever, sweats, decreased libido, dry mouth, insomnia, worrying, irritability and difficulty concentrating (Glare).

The symptom status of PLWHA is related to psychological well-being and quality of life (Coleman & Holzemer, 1999; Sousa, Holzemer, Henry & Slaughter, 1999). Linn, Anema, Hodess, Sharpe and Cain (1996) also acknowledged the relationship between symptoms (in addition to personal and social resources), the client's self appraisal of their health status and psychological distress. In their study of 255 adults with HIV, they found the symptoms of nightsweats, rashes, weight loss, diarrhoea, sore throat, muscle weakness, fever and chills impacted the greatest extent on the client's perceived health status. They emphasised the importance of health care workers focussing clinical attention towards symptoms and personal and social resources to assist the client maintain a positive self perception of their health status. While it is clear this is an inappropriate goal for those in the advanced stages of HIV/AIDS who are overwhelmed by their illness, these strategies could do well in supporting them to manage their issues and to remain at home.

2.5.3.1 Pain Experienced by PLWHA

Pain is a common and progressive problem in PLWHA (Eldridge, Severance-Lossin, Nicholas & Leuner, 1994; Glare & Cooney, 1997; O'Neill & Sherrard, 1993) (Tables 2.8 and 2.9). Common causes of pain include peripheral neuropathy, malignancies, diarrhoea, CMV, MAC, KS and

arthralgia. Common sites or types of pain include headache, and pain of the abdomen, anorectal area, oesophagus, feet back and mouth. Pain frequently presents management difficulties (Table 2.10). These include persistent abdominal pain of unknown cause, IDU, peripheral neuropathy and the terminal phase of illness. HIV/AIDS can cause a wide range of pain-related syndromes, and PLWHA often experience more than one pain. This can cause discomfort, disability, distress, depression (Penfold & Clark, 1992; Singer et al., 1993), weakness and fatigue (Newshan & Wainapel, 1993), in addition to impacting negatively upon the client's perceived body image and social supports (Glare & Cooney, 1997).

Table 2.8 Documented Characteristics of Pain in PLWHA

Incidence/Site/Type/Cause	Reference
<p>Incidence: 25% 'asymptomatic' clients, 40-50% ambulatory clients, >80% hospitalised clients</p> <p>common examples: peripheral neuropathy, headache, abdominal pain due to enteric pathogens, malignancies and acalculous cholecystitis, perianal pain due to herpes simplex virus, mouth pain.</p>	<p>Glare & Cooney (1997)</p>
<p>Headache is a frequent symptom and causes include disease of the central nervous system (eg encephalitis, meningitis, neoplasm), anxiety, migraine or sinus infection.</p>	<p>O'Neill & Sherrard (1993)</p>
<p>About 15% present with acute, severe abdominal pain requiring urgent evaluation. Causes include diarrhoea, cytomegalovirus, mycobacterium avium complex, medication, pancreatitis, cholangiopathy, lymphoma.</p>	<p>Sievert, Shaw & Edwards (1997)</p>
<p>Common causes of anorectal pain: infection, cancers, lymphoma, Kaposi's Sarcoma, trauma, fissures, fistulae, abscesses, haemorrhoids.</p>	<p>Penfold & Clarke (1992)</p>

Table 2.9 Documented Studies of Pain in PLWHA

Most Common Site/Type/Cause of Pain	Study
Abdominal, neuropathic, diffuse pain, headache, back pain, skin pain, anorectal pain, chest pain, oropharyngeal pain, procedure pain, cancer pain, odynophagia.	Glare (1994) Sydney, Australia (n=55)
Abdominal pain, neuropathic pain, oesophagitis, headache, cutaneous Kaposi's Sarcoma, back pain, bone and joint pain, post herpetic pain.	Newshan & Wainapel (1993) New York City, USA (n=100)
HIV-related headaches, herpes simplex, peripheral neuropathy, back pain, herpes zoster, AZT-induced headaches, throat pain, arthralgia.	Singer et al. (1993) Los Angeles, USA (n=240)
Incidence: 40% clients on admission Pain sites: lower extremities, back, abdomen, head, coccyx/rectal area, upper extremities, thorax, mouth, generalised body, bone. Self reported impact: activity restriction, reduced concentration, disturbed sleep, contributed to irritability and depression.	Eldridge et al. (1994) Boston, USA (n=50)

Table 2.10 Documented Problems in the Pain Management of PLWHA

Problem	Reference
Difficult management problems 33% of all clients: persistent abdominal pain of uncertain cause, pain management in injecting drug users and clients on methadone maintenance, rapid escalation of opioid doses in anguished, dying clients, strong opioid use in clients with dementia.	Glare (1994)
Problem areas include visceral pain (particularly oesophageal and abdominal), peripheral neuropathies, headaches, and arthropathies. Abdominal pain is frequently troublesome because of difficulties in diagnoses and treatment.	O'Neill & Sherrard (1993)
Breakthrough pain: in between analgesia dose or incident/activity related eg movement, wound care, procedure. Some pain eg neuropathic is not very responsive to opioids. Peripheral neuropathy is a therapeutic challenge.	Glare & Cooney (1997)
Pain in the terminal phase of illness. Causes include central nervous system involvement, dyspnoea, immobility, malignant or infectious process.	Schietinger (1986)

The best form of palliation is to directly treat the identified cause of pain, in addition to the related cognitive, psychological and sociocultural components (Eldridge et al., 1994; Glare & Cooney, 1997; Penfold & Clark, 1992). Surgical interventions, however, present a high risk for clients with advanced HIV/AIDS and are usually best avoided (Sievert et al., 1997). In cases where the cause is unknown or unable to be effectively treated, symptomatic measures may be adopted (Glare & Cooney).

2.5.3.2 Other Symptoms Experienced by PLWHA

It is important to investigate the cause of all fevers occurring in PLWHA. Of 75 patients admitted to a specialist HIV/AIDS Unit in London with pyrexia of unknown origin between 1989 and 1993, 97% were caused by infection (mainly mycobacterial, bacterial and fungal) (Miller, Hingorami & Foley, 1996).

Lethargy can be debilitating and have many causes. These include physical exertion, stress, inadequate rest, a hectic schedule, feeling overwhelmed, disturbed sleep, boredom, anxiety, depression, acute or chronic infections, malignancies, nutritional deficiency, anaemia, cardiopulmonary dysfunction and lack of energy (Bennett, 1988).

Severe weight loss can adversely affect PLWHA. Summerbell, Perrett and Gazzard (1993) retrospectively reviewed the charts of 420 PLWHA who attended a London outpatient clinic between June, 1990 and June, 1991. Of the 121 patients (29%) who had experienced weight loss, 71% had an identifiable cause, the most common being opportunistic infections including oral candida (47%), psychosocial factors (17%) and drug related problems (7%). This study also identified that opportunistic infections related to diarrhoea (16% of the sample) caused the greatest degree of weight loss. Unexplained weight loss was found to be uncommon and most

likely to be experienced by those with a more competent immune system who had symptoms with an unidentified cause.

2.5.4 Drug Allergies and Intolerances Experienced by PLWHA

Drug allergies are more common in PLWHA than other patients, particularly to the sulfonamide drugs trimethoprim, sulfamethoxazole, sulfadiazine and dapsone which are commonly prescribed for the treatment or prophylaxis of PCP and toxoplasmic encephalitis (Carr & Garsia, 1997; Wong & Shumack, 1997). Other drugs to which hypersensitivity is seen to develop are clindamycin, atovaquone, penicillins, cephalosporins, thiacetazone, nevirapine and delavirdine, with the most important of these being the b-Lactams, anticonvulsants and anti-tuberculous agents. The most common manifestations of hypersensitivity include fever and the development of an erythematous, maculopapular pruritic rash. Other less common reactions include nephritis, hepatitis, pneumonitis, anaphylactoid or anaphylaxis (Carr & Garsia) leukopenia, thrombocytopenia and vasculitis (Wong & Shumack). PLWHA may develop a hypersensitivity to multiple drugs.

Common side effects of many medications prescribed to PLWHA include liver disease (Sievert et al., 1997) and cytopenias (Ownby, 1995). Common medications known to cause cytopenias include the sulfonamides, pentamidine (treatment of PCP), ganciclovir (treatment of CMV), flucytosine, amphotericin b (treatment of fungal infections), alpha interferon (treatment of KS) and zidovudine (antiviral agent) (Ownby). The treatment of depression may also be restricted by hypersensitivity (O'Dowd, 1995).

2.6 Lifestyle and Psychosocial Aspects of PLWHA

An overview of the lifestyle and psychosocial aspects of PLWHA is presented to provide a background to the demographic and psychoemotional parts of the first research question and the third question as stated in Section 1.6. In the absence of a vaccine or cure, HIV will continue to impact on those at risk as well as those who care for them (Britton, Zarski & Hobfoll, 1993). The health of individuals throughout their lives is strongly affected by their social and economic circumstances (National Health Strategy, 1992). In health service delivery it is important to adopt a holistic approach which addresses the social determinants of health. These include stress, early life, social exclusion, work, unemployment, social supports, addiction, food and transport (World Health Organisation, 1998; Marmot, 1999).

2.6.1 Employment, Income and Accommodation of PLWHA

The HIV Futures 1 study (Ezzy, de Visser, Bartos, McDonald, O'Donnell & Rosenthal, 1998) involved a survey of 925 PLWHA in Australia in 1997, of which 404 were from NSW. Of those in NSW, 80% lived in Sydney, of which 68% were living in an inner suburb, not far from the research setting. The survey found little difference between those in NSW compared to those in other areas of Australia. Of the PLWHA in NSW, less than half were in paid employment, with the majority reporting their main source of income was a government benefit. Twenty three percent of those living in Sydney, and 55% of those living in other areas of NSW were identified as having an income below the poverty line. Of all those completing the survey in NSW, 47% lived in public housing, 33% either owned or were purchasing their home, and 15% lived in private rental accommodation (Australian Research Centre in Sex, Health and Society [ARCSHS], 1999). These figures reflect the disadvantaged socioeconomic status of many PLWHA.

2.6.2 Sexuality and PLWHA

The fact that HIV infection has been limited mainly to homosexual men has perpetuated the image of HIV as a 'gay' disease in Australia. Although HIV is increasing among women, the overall numbers remain low compared to homosexual men and appear to have had little impact on the perceptions heterosexuals have of HIV/AIDS.

The process of coming to terms with one's own homosexuality can result in a shift in social networks and personal identity and is often a precarious time. An awareness of male sexuality is necessary to understand the HIV/AIDS pandemic and enable health care workers to offer assistance to men who are undertaking this transition (Pethebridge & Plummer, 1997). There is a dearth of information describing the transmission of HIV from female to male and from female to female, although the former probably represents less than 1% of the cumulative prevalence in Australia. An additional risk factor of sexual activity to be considered in HIV infected women is menstruation (Stewart, 1997).

HIV/AIDS confronts us with our naivete and discrimination about sexuality and its expression by the identification of the risks of HIV transmission through specific sexual practices (for example, anal intercourse in heterosexuals), on which preventative strategies must focus (Mann, 1993). An important goal of the health care worker is to reduce the risk of HIV transmission to the uninfected sexual partner while offering support to the relationship (Stewart, 1997). Adler (1993, p. 364), acknowledges that convincing the community to change their sexual behaviours is an: "...extraordinarily difficult task [that] needs a variety of approaches which extends far beyond the usual domain of science and medicine". However, this author points out that this is an area routinely addressed in the healthcare field of STDs. Further research is required in the area of sexuality which focuses upon how sexual behaviour is formed,

modulated and altered, as well as the area of discrimination which increases the risk of HIV transmission in our communities (Mann, 1993).

2.6.3 Substance Use and PLWHA

The sharing of equipment used for IDU is one of the most effective ways of transmitting HIV, more so than unprotected sex (Wodak & van Beek, 1997). Drug users often take multiple drugs including IV narcotics and amphetamines, oral benzodiazepines, analgesics and alcohol and inhaled cannabis and tobacco (Wodak & van Beek). Drug use has been associated with an increased risk of HIV transmission due to unsafe practices (Ostrow et al., 1990) which may be associated with low self esteem (Visintini et al., 1995). Complications which may occur include the increased likelihood of drug interactions, the difficulty of controlling pain when narcotics are used, and the IDUs greater risk of developing opportunistic infections (Ross, 1997).

In addition to HIV, IDUs may also have multiple social problems that include legal, financial and/or living arrangements (Wodak & van Beek, 1997). Clients may use drugs in response to the pressures of their illness and this can create further problems (Ross, 1997; Wodak & van Beek). Sexual partners of IDUs with HIV are also at risk of infection, with female IDUs being more likely to have sexual relations with male IDUs (Rose, 1993).

As many IDUs are unable or unwilling to abstain from drugs, a harm reduction approach has been used to assist in the prevention or minimisation of the resultant health and social problems (Catalan, 1995; Wodak & van Beek, 1997). Fortunately, in Australia, where proficient primary health services are well established (Pethebridge & Plummer, 1997), the spread of HIV amongst IDUs has been limited and late presentation of those who are infected within this group is rare (Wodak &

van Beek). Methadone has been shown to be effective in decreasing the spread of the AIDS epidemic (Krause, 1993) and Australian methadone maintenance programs have had a stabilising effect on the lifestyles of many IDUs (Wodak & van Beek).

Thompson, Nanni and Levine (1996) found that alcohol intake was related to the number of stressors people with HIV had, and smoking and unsafe sexual practices were related to their experience of perceived stress. Attitudes concerning the use of drugs, including alcohol and tobacco, are instrumental in determining the therapeutic potential of the nurse/client relationship (Naegle, 1994).

2.6.4 Psychosocial Aspects of PLWHA

The majority of people with HIV are young and most are faced with severe psychosocial stressors (Penfold & Clark, 1992) that include illness resulting in changes in personal autonomy, work, social life, and income (Catalan, 1995). HIV/AIDS impacts upon all areas of society through deaths, loss of productivity, psychological responses and prejudices (Kuehnert, 1991). People newly diagnosed with HIV have the profound effects of the stress of this condition and its prognosis as well as the reactions of their partners, friends, family, colleagues and community to contend with (Carnegie & Rutter, 1992; Miller & Riccio, 1990; Salzer et al., 1987).

Due to the socially unaccepted risk factors of homosexuality, sexual promiscuity and illicit drug use, HIV is often associated with deviant behaviour (Bingham & Stewart, 1997) and is therefore a socially stigmatised disease (Judd & Mijch, 1994; Ross, 1997; Stewart et al. 1997). The experience of having HIV/AIDS is profoundly affected by the social context in which preventative strategies, infection, illness, treatment and

care take place (Bor, Elford, Hart & Sherr, 1993; Carney, 1990; Gillieatt, Mallal, French & Dawkins, 1992; Layzell & McCarthy, 1992).

Discrimination (for example by personal rejection or denial of employment or housing), may damage the self esteem and exacerbate the feelings of depression of the client with HIV, further compromising their physical health and emotional well-being (Ross, 1997). PLWHA, in parallel with society, are faced with ethical dilemmas related to substance use, chronic illness, death, discrimination, finances, health care, personhood, relationships, service and sexuality (Cameron & Crisham, 1994).

A study in Perth of 106 people diagnosed with AIDS between January 1988 and July 1991 (Gillieatt et al., 1992) identified late presenters as more likely to develop PCP and to die from their first AIDS-defining illness, reflecting their delay in diagnosis and treatment. Common reasons given by late presenters for not seeking treatment earlier included concerns about confidentiality and the impact their HIV status might have on themselves, their partners and their family. None of the late presenters were aware of the improved treatments for HIV disease, including antiretroviral and prophylactic medications.

As AIDS is infectious, chronic and fatal, the way PLWHA resolve these dilemmas can impact greatly on those around them and society as a whole. In Australia, the urban homosexual community was already set up to oppose discrimination when HIV emerged. As a group, they took on a strong activist role and participated in the development of the political and medical responses to HIV/AIDS and remain a powerful and well-informed force (Bingham & Stewart, 1997).

2.6.5 Social Supports and PLWHA

Social supports impact on the health of individuals (Stewart, 1993). Effects include personal competence, health maintenance behaviours, coping behaviours, perceived control, positive affect, sense of stability, recognition of self worth, decreased anxiety and depression and psychological well-being (Langford, Bowsher, Maloney & Lillis, 1997). Commonly, the communities where AIDS clients are discharged in USA do not have adequate social support systems to counteract the isolation which they often experience (Carney, 1990). Prejudice and fear may leave PLWHA without social supports and hence contribute to their isolation (Carnegie & Rutter, 1992; Judd & Mijch, 1994; Kelly et al., 1993), exacerbating the stress of being HIV positive. This is particularly so for 'closet' homosexuals and drug users (Ross, 1997). However, even those infected with HIV heterosexually or through medical intervention can also be faced with discrimination and challenges to their social identity. Hurley and Ungvarski (1994) conducted a retrospective study of 244 clients with HIV/AIDS from a home health agency in 1991 in New York and found that 50% lived alone and 17% had no telephone. The telephone is an important link between the client and the community nurse, as well as their other support systems.

Each PLWHA represents a family that is also affected by the disease. HIV/AIDS can challenge the traditional concept and functioning of the family. They, like the client, can also experience social stigma, isolation resulting from secrets, shame, guilt, loss, despondency (Bor et al., 1993), grief and shock over the infection, and its implications, sadness, anxiety, helplessness, anger (Lippmann, James & Frier, 1993) and fear. It is important that health care professionals feel comfortable addressing these issues (Moore & Appleby, 1993). Families will rely on their usual coping mechanisms during a crisis such as a terminal illness, and the inclination

for it to either bring them closer or drive them apart is magnified by HIV/AIDS illness (Carney, 1990).

In comparison to hospital, family and friends usually become more involved in the client's care when they are at home. As the number of long term chronically ill people remaining at home generally increases, so does the burden on relatives and informal carers (Armitage, 1995; Lippmann et al., 1993), particularly if the PLWHA demented (Bennett, 1988). A Canadian study by Friedland, Renwick and McColl (1996), found that close friends provided the majority of the support to 120 people with HIV, and that this support was more beneficial to clients than that given by family members. This, too was the finding of an Australian study of 100 IDUs in 1991 (Stowe, Ross, Wodak, Thomas & Larson, 1993). Carers undertake the multiple roles of running the household, providing physical and therapeutic care and mediating between the PLWHA and others. It is the client and their significant others who are faced with preparing for death and the establishment of these plans assists in the grief process (Lippmann et al.).

Carers also experience the stressors of HIV/AIDS disease which include physical, social and emotional constraints (for example, isolation from support network, financial hardship, reduced sexual options) (Miller & Riccio, 1990) and repeated crises can exhaust their resources (Bennett, 1988). Some people who are expected to care will feel genuinely motivated to do so, but feel concerned and ill-equipped (Arkell, 1993). The carer or family may experience feelings of guilt because of their own desire for the PLWHA to die (Lippmann et al., 1993), their inability to provide ongoing care (Carnegie & Rutter, 1992), or a sense of responsibility for transmitting HIV to the PLWHA (Bennett). The majority of carers interviewed in an Amsterdam study stated they experienced physical and psychological stress and lack of freedom (Moons et al., 1994). One of the greatest

differences identified between carers who were able to cope and carers who were not, was the support they received from friends and health care professionals (Research Institute for Consumer Affairs and Disabilities Study Unit, [RICADSU], 1990).

2.7 Psychoemotional Aspects of PLWHA

An overview of the psychoemotional aspects of PLWHA is presented to provide a background to this part of the first research question and the third research question, as stated in Section 1.6. Living with HIV/AIDS is associated with significant levels of stress and depression (Thompson et al., 1996). Around the study time, HIV/AIDS and the risk of HIV infection was the cause of serious stressors to an increasing number of groups in our society (Britton et al., 1993).

It is acknowledged by nurses experienced in the area of HIV/AIDS (Grimes & Grimes, 1995) that a substantial proportion of PLWHA experience a broad range of psychological symptoms which may be transient or persistent (Catalan, 1995). Responses may include grief, despondency, resentment (Lippmann et al., 1993), somatisation, obsessive compulsive disorder, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychotism, sleep and appetite disturbance, guilt feelings and thoughts of death and dying (Kennedy, Skurnick, Foley & Louria, 1995). In a retrospective chart review of 244 clients with HIV/AIDS discharged from a home health agency in 1991 in New York, clients were identified as experiencing memory deficit (34%), depression (28%), anxiety (27%), impaired judgement (18%), substance abuse (18%), insomnia (16%) and agitation 11% (Hurley & Ungvarski, 1994).

Anger, guilt and self pity can be destructive emotions which may damage the relationships the client has with their family, partner, friends, health care providers and colleagues, having a negative impact on their career and

living arrangements (Grimes & Grimes, 1995). Issues related to psychological signs and symptoms are presented in Table 2.11 and include pain, grief, pre-existing psychological conditions, social stigma, illness, social supports and sexual expression.

As people find out about their HIV status at varying stages of their illness, psychological responses cannot be related to physical condition alone (Grimes & Grimes, 1995). While we all know we will die one day, it is difficult for us to accept this reality and live our life in the knowledge that we are likely to experience illness and death in the foreseeable future (O'Dowd, 1995). Everyone's journey and response varies (Grimes & Grimes), and acquisition of HIV will also present differing issues amongst homosexuals, IDUs, haemophiliacs, medically acquired and heterosexually acquired individuals (Glare, 1994).

Berk and Nanda (1994) state that due to the difficulties of scaling the psychosocial and behavioural needs of PLWHA, it is inappropriate to attempt to measure them through the use of one universal tool. They assert it is only acceptable to assess the level of need on an item by item basis. Never-the-less, a Mental Adjustment to HIV (MAHIV) Scale has been developed from the Mental Adjustment to Cancer Scale (Watson et al. 1988).

In their Australian study, Ross, Hunter, Collins and Begley (1994) adapted the MAHIV Scale and found that, when compared to clients with cancer, PLWHA have a stronger belief that they can personally influence the course of their disease. Despite the need for further research, they believed that their MAHIV Scale was useful in assessing the impact of disease progression on mental adjustment. The MAHIV Scale by Chidwick and Borrill, (1996) identified that PLWHA who had great difficulty coping

Table 2.11 Some documented Predictors and Influences of Psychological Signs and Symptoms of PLWHA

Predictors and Influences	References
Depression: Individual stressors (particularly those experienced in the past month in the areas of finances and relationships), perceived stress and the illness.	Thompson et al. (1996)
Gender: Of 100 heterosexual couples where at least one was HIV positive, women experienced more distress than men.	Kennedy, Skurnick & Louria (1995) n=200
Diagnosis of a life-threatening condition and uncertainty surrounding the psychological and medical treatment of HIV/AIDS and its prognosis eg fluctuating illness affecting finances. Coping strategy influences: the time since diagnosis; the perceived physical health of the individual; and by social support.	Chidwick & Borrill, (1996) n=23
The prospect of major negative life events eg chronic illness, pain, disability, premature death, loss of employment, financial insecurity and independence.	Fleisham & Fogel (1994); Kelly et al. (1993)

Table 2.11 (continued) Some documented Predictors and Influences of Psychological Signs and Symptoms of PLWHA

Predictors and Influences	References
Fear of pain and the unknown, sadness of leaving loved ones, unfinished life tasks.	O'Dowd, M.A. (1995)
Adjustment disorder and non-adherence with medical treatment: Pre-existing, psychological conditions eg low self esteem, promiscuity, poor social skills and drug or alcohol dependence.	Stewart et al. (1997)
Additional emotional needs and expectations exist in clients, their families and carers because HIV is incurable, affects mainly young people and carries a social stigma.	Scott & Irvine (1997)
Coping with a chronic health threat: Available social and relationship supports, preexisting general coping style, competing life stressors unrelated to HIV illness, extent of clinical illness symptoms.	Kelly et al. (1993)
Physical suffering, social stigma, disfigurement, loss of a sex life, and conflicts with reproductive choices, fear of untimely death, changing health status.	Grimes & Grimes, (1995); Glare (1994)

were generally diagnosed less than two years ago, were unwell and perceived themselves to be unwell and lacked a satisfactory social support network. Characteristics of those with effective coping abilities were a positive attitude about the future and their place in it. Chidwick and Borrill stated that while the MAHIV Scale needed further piloting, it was an effective research tool in identifying clients who coped effectively. However, there appeared to be a strong relationship between coping and the wellness and prognosis of clients in the scale, making its usefulness in clients with advanced HIV/AIDS questionable.

The individual's response to illness is as important as the illness itself and resultant behaviour (Ross, Hunter, Condon, Collins & Begley, 1994). Psychological disturbance can have a dramatic impact on clinical symptoms (Marriott & McMurchie, 1997) and related behaviours can affect the course of illness for example, delayed treatment and increased mortality may occur when clients are depressed or in denial (Ross, 1997). The early identification of people likely to experience psychological difficulties is important.

2.7.1 Depressed Mood in PLWHA

Depression is a type of grief reaction to sustained and imminent losses which can have varying effects on the client depending on current illness, personality, life situation, social supports and concurrent stressors (Judd & Mijch, 1994). It can significantly influence the client's physical illness and sense of well-being, and depressed mood in the absence of clinical depression, can still compromise physical health (Scheier & Bridges, 1995). Depression is a serious, common and treatable condition amongst PLWHA (Katz et al. 1996). While depressive symptoms occur commonly in those who are physically unwell (Mierlak et al., 1995), its severity has implications for clinical management.

In an American study of 736 PLWHA, Fleisham and Fogel (1994) used six items from the Centre for Epidemiological Studies Depression (CES-D) Scale (Radloff, 1977) to assess coping behaviours and depressive symptoms. They found that over 40% of the sample had clinically significant depressive symptoms, although they felt that the scale was not an indicator of DSM-IV (APA, 1994) depression and should be interpreted as an indicator of psychological disturbance or depression.

On assessment of 32 PLWHA on admission and discharge from hospital for a medical illness, Mierlak et al., (1995) found that nearly half with severe depressive symptoms based upon the Beck Depression Inventory (Beck, Ward & Mendelson 1961) would probably fit the criteria for the DSM-IV disorders. They found that PLWHA with moderate depressive symptoms on admission to hospital tended to improve as their physical problems resolved. It was postulated this was related to the improvement of physical status and the end of the debility, pain and disruption to life the hospitalisation caused. However, those with severe depressive symptoms on admission still experienced this on discharge despite physical improvement, indicating the depression may be a comorbid mood disorder.

Mierlak et al. suggests that the initial presentation of depression may give some indication of aetiology and appropriate management strategies. However, this author points out unresolved depression may also reflect the effects of chronic and progressive HIV illness which are complex and not addressed by the treatment of acute conditions. Table 2.12 outlines some identified causes, indicators and predictors of depression. They include physical disfigurement, illness, grief and social supports. Depression in PLWHA needs to be detected before treatment can be offered (O'Dowd, 1995). There is a need to increase the assessment and intervention for depression amongst PLWHA (Katz et al. 1996).

Table 2.12 Some Documented Causes, Indicators and Predictors of Depressed Mood in PLWHA

Causes/Indicators/Predictors	Reference
Skin cancer (particularly when visible) severe scarring and weight loss leading to loss of self esteem and avoidance of social situations.	Catalan (1995)
Overwhelming consequences of illness.	Grimes & Grimes (1995)
Significant losses such as death of a loved one or friend, lifestyle change, body image changes due to illness or ageing.	Valente & Saunders (1994)
Personal perceived health status and the symptoms of hearing loss, numbness, sore throat, muscle weakness, heartburn, fever, and difficulty swallowing.	Linn, Anema, Hodess (1996)
Multiple losses and psychosocial stressors associated with advanced illness.	Judd & Mijch (1994)
Persons with HIV-related symptoms, social support, who were unemployed and with a CD4 count <200.	Katz et al. (1996) (n=475) USA

2.7.2 Distress and Anxiety in PLWHA

Grimes and Grimes (1995: p27) define anxiety as the “inability to deal with normal functions of life”. Adjustment or acute stress reactions have a significant impact on the lives of PLWHA (Miller & Riccio, 1990). Some

documented causes of distress in PLWHA are shown in Table 2.13. They include fear of dementia, reduced quality of life, weight loss and symptoms.

Table 2.13 Documented Causes and Predictors of Distress in PLWHA

Causes/Predictors	Reference
Fear of developing dementia.	Catalan (1994)
Reduced quality of life due to HIV-related physical symptoms, limitations to physical functioning.	Fleisham & Fogel (1994)
Weight loss is amongst the most feared and devastating consequences of HIV infection.	Kelly, Lloyd & Kemp, (1997)
Threat or actual loss of resources.	Britton et al. (1993)
Fear of loss of confidentiality may cause the client, carer or family to decline outside assistance.	Hall (1994)
Somatic symptoms eg pain, diarrhoea, and visual impairment Side effects of treatment.	Judd & Mijch (1994)

Increased distress is frequently associated with behaviours such as denial, wish-fulfilling fantasy or emotional venting (Fleisham & Fogel, 1994). Other indicators of distress can include pacing, clenched fists, tight jaw, coiled body position, tachypnoea, tachycardia, diaphoresis, acknowledgment of problems at home or at work, reduced social interaction, insomnia, and/or changes in eating habits. While anxiety may be paralysing, the outcome can be positive if it motivates people to take constructive steps to work through their issues and cope with their infection in a positive manner (Grimes & Grimes, 1995).

2.7.3 Grief Issues Experienced by PLWHA

Grief is defined as an emotional response to loss (Salyer et al., 1987). PLWHA experience multiple losses throughout their illness including the death of others and their own anticipatory grief (Bennett, 1988; O'Dowd, 1995; Pethebridge & Plummer, 1997).

A London study of 90 PLWHA referred for counselling by doctors, found that 43% of the clients spontaneously commenced their session with bereavement issues despite this being acknowledged as an issue for only 28% on referral. The bereaved clients in this study had experienced an average of 12.9 deaths each of which 94% were related to HIV/AIDS. Furthermore, 65% of the clients related their bereavement to their own death (Sherr, Hedge, Steinhart, Davey & Petrack, 1992). The emotions associated with bereavement identified in the abovementioned study were diverse and included (in sequence) anger, shock (40%), guilt (44%) and depression (over half). Pethebridge and Plummer (1997) concurred with this finding, stating the emotional response to grief can be severe and long term and may lead to low self esteem and social isolation. They state the incidence of guilt may be associated with self blame and survivor guilt. While anger may have negative physical manifestations, research suggests that suppressed emotions may also lead to disease (Scheier & Bridges,

1995). PLWHA can experience anger as part of the grief process and may direct it at health care providers (Sherr et al., 1992).

Grief can also involve denial, anxiety, confusion and a physiological reaction, although the identified emotions and stages overlap and clients may move on from or revisit them (Salyer et al., 1987). PLWHA often present with many of the indicators of complicated grief. These include young age; the tendency for bereavement to be multiple; the loss of a partner not recognised as a spouse; illness and other losses of the bereaved person; the social stigma of HIV/AIDS, exposure and disclosure of previously hidden issues; discrimination; and limited available support (Glare, 1994; Sherr et al., 1992).

2.7.4 Lack of Adherence to Suggested Interventions by PLWHA

PLWHA's acceptance to undertake interventions reflects the connection between the scientific and psychoemotional aspects of HIV/AIDS disease. It involves the client changing their behaviour so they are able to commit and conform to an imposed schedule (Batrouney, 1997).

Adherence to prescribed medication has a significant impact on the course of HIV/AIDS disease as some opportunistic infections can be treated prophylactically and the progression of HIV can be stalled. Furthermore, Delaney et al. (1994) state that 'compliance' with medication would make medical management easier and reduce preventable hospital admissions. Lack of adherence of clients to medication may include not taking it as prescribed or taking additional or alternative medication which is contraindicated (Ross, 1997). It may also present as missed appointments, lack of healthy lifestyle changes, not following instructions (Grimes & Grimes, 1995), refusal of referral to community nursing services, and misinforming health care workers of intentions (Armitage, 1995).

Documented factors that may influence the client's level of willingness to undertake suggested interventions are given in Table 2.14. They include denial, anger, depression, education, culture, and side effects and difficult medication regimes.

2.8 Health Care Needs of PLWHA

An overview of the health care needs of PLWHA is presented to provide a background to the forth research question, as stated in Section 1.6. Clinical care of members of the community who have or are at risk of HIV infection is a daunting task (Friedland, 1995). The goals of health care providers are to improve the level of comfort, function and quality of life of PLWHA (Penfold & Clark, 1992; Rose & Clark-Alexander, 1996) and they are faced with the challenge of providing quality care within budgetary constraints (Friedland; Sowell, 1995).

The long, progressive and erratic course of HIV/AIDS disease results in a wide variation in the amount of time and frequency of home care required by PLWHA (Moons et al., 1994). The implementation of creative and cost effective strategies that reduced the need for hospitalisation and effectively addressed the client's holistic needs were increasingly achieved through the improvement of treatments, prophylactic medication (Friedland, 1995) and education promoting self care (Moore & Appleby, 1993).

Table 2.14 Documented Factors which could Influence PLWHA's Acceptance of Suggested Interventions

Influencing Aspects	References
Psychological status eg denial, anger and depression. A trusting relationship with the doctor. A sense of personal empowerment in managing the disease.	Ross (1997)
A reason for compliance not based on coercion or force. Recognition of HIV as a serious chronic disease requiring continual maintenance. Physical, psychological, financial and other barriers to assume the health behaviour. Lack of systematic, logical, practical and ongoing treatments education.	Batrouney (1997)
Denial leading to inability to take action.	Grimes & Grimes (1995)
Cultural differences.	Armitage (1995)
Counselling and education regarding medication.	Delaney et al. (1994)

Table 2.14 (continued) Documented Factors which could Influence PLWHA's Acceptance of Suggested Interventions

Influencing Aspects	References
Use of a dosette box for medication.	Haire (1997); Schmidt (1992)
Partnership between the doctor pharmaceutical company and the consumer based on informed choice.	Gallagher (1997)
Use of denial and helpless coping (more commonly found in personality disorders) affecting the relationship with the doctor.	Perkins, Davidson, Leserman, Liao & Evans (1993)
Belief that medication is not required when feeling well. Side effects causing discomfort. Complex medication regime, particularly if experiencing confusion or forgetfulness.	Schmidt (1992)
Education level and cognitive impairment. Amount of medications and interactions.	Ungvarski, Scimidt & Neville (1994).

The maintenance of standards is important when care is moved from the hospital to the community and it is essential to ensure adequate resources are available and the client is accepting of this way of caring (Arkell, 1993). Available clinical structures and expertise also determine the quality of clinical care. The inequality and inequity in service provision in developing countries is an example of the impact of these factors (Friedland, 1995).

While client satisfaction is an important aspect of the management and evaluation of HIV/AIDS resources and initiatives, it is an indirect indicator of quality care (Meeks-Festa et al., 1994). However, it may also be that customer satisfaction is indeed a strong indicator of quality nursing care from a holistic perspective. Scott and Irvine (1997) found PLWHA prefer their health care workers to:

- ♦ Adopt a non-judgemental approach.
- ♦ Offer informative communication.
- ♦ Maintain confidentiality.
- ♦ Display tolerance to complementary therapies.
- ♦ Include them in decision-making.
- ♦ Be open in discussing issues related to death and dying.

All members of the community need to know their health care workers value their life and well-being. This is magnified in PLWHA due to the social stigma associated with their disease (Scott & Irvine, 1997). HIV/AIDS has challenged health care workers to balance the rights of PLWHA with the promotion of public health, and it has highlighted the value of collaboration with the community and consumer-led activism, as well as the detrimental effects of prejudice and discrimination (Bingham & Stewart, 1997).

Arkell (1993) identified a major need for health care workers to prevent the transmission of HIV. Clinically, HIV/AIDS has heralded a change in infection control practices. These changes are not determined by the clients diagnosis, but are implemented so health care workers can protect themselves and their clients from the risk of transmission of HIV and other blood borne viruses (Moons et al., 1994).

As some illnesses are preventable through health teaching (Ungvarski et al., 1994; Ownby, 1995), clients with HIV need to be educated so they can make informed decisions regarding their lifestyle and treatment choices throughout the course of their illness (Scott & Irvine, 1997). PLWHA often have complicated health histories, illnesses and treatment regimes (Ungvarski, 1994). As treatments may be experimental, a lot of contradictory information exists for health care workers (Arkell, 1993). The client with HIV/AIDS may be as well informed as the nurse about their condition (Grimes & Grimes, 1995), and actively participate in the decision-making process regarding their treatment options (Anderson, O'Connor, MacGregor & Schwartz, 1993; Layzell & McCarthy, 1993). Some may choose to investigate and trial some alternative therapies (Anderson et al., Grimes & Grimes) and health care workers should be aware of their clients' interest and assist them to achieve the desired outcome.

Generally, the long term care of PLWHA involves monitoring their immune function, continued antiretroviral therapy and prophylactic medication, symptom control and the prompt diagnosis and treatment of presenting problems (Glare, 1994). To effect early intervention and treatment, it is important that clients are knowledgeable about their immune status and about the health problems to which they are most vulnerable (Stewart et al. 1997). Health service delivery needs to be multidisciplinary, collaborative, communicative (Bennett, 1988; Turjanica, Ardabell, Schiffer,

Poirier & Brodeur, 1994), comprehensive, competent, compassionate (Friedland, 1995) and flexible to allow it to effectively respond to the changing individual needs of PLWHA (Foley et al., 1995; Layzell & McCarthy, 1992). Treatments need to encompass the medical, psychological, social and spiritual aspects of care (Sowell, 1995). Due to the complex nature of the disease, members of the home health care team need access to resource people who are knowledgeable about HIV/AIDS and home care to provide education and professional support (Schmidt, 1992). Collaborative efforts should avoid unwanted duplication of service (Layzell & McCarthy).

2.8.1 Palliative Care of PLWHA

Venning (1990) states we have lost the familiar reality of death realised at the turn of the 19th century, when it was commonplace for people to die at home, surrounded by their loved ones. Palliative care aims to relieve pain and suffering in clients with advanced illness, increase the quality of life and support carers and relatives (Catalan, 1995; Glare & Cooney, 1997).

In 1997, HIV/AIDS represented five percent of referrals to urban palliative care services and up to 25% in some areas such as the inner city area of Sydney (Glare & Cooney, 1997). HIV/AIDS has changed the face of palliative care from a narrow, hospice based cancer perspective where active treatment was not routinely provided to a flexible multi-setting service where the treatment is often disease specific and based on the wishes of the client and relatives. The care of clients with terminal HIV/AIDS disease presents challenges not usually encountered in traditional palliative care practice and includes invasive investigations and active treatments, difficulty in determining prognosis and the consideration of complex issues when making decisions regarding interventions (Glare, 1994). An Italian study (Manfredi, Mastroianni, Coronado & Chiodo, 1996) demonstrated that the availability of new

treatments influenced the care of these patients in the last weeks of their life to a more curative approach rather than palliative.

In the terminal phase of their illness, PLWHA are usually so immunocompromised that they experience multiple acute and chronic disseminated conditions (Schietinger, 1986) on the background of increasing debility, weight loss, deterioration in cognitive function, febrile episodes and often dyspnoea at rest (Glare, 1994). In comparison with other palliative care clients, PLWHA have a higher rate of affected younger people, multi-system disorders, variation of disease pattern and goals of treatment, unpredictable terminal phase, polypharmacy, dementia, substance abuse, psychosocial and psychiatric problems. In cases where the cause of symptoms cannot be diagnosed or treated, the symptoms themselves are treated.

As polypharmacy may impair quality of life, it is important the client's medication regime is reviewed regularly (Glare & Cooney, 1997). Open discussion of realistic choices and options with regard to treatment and arrangements should be encouraged (Scott & Irvine, 1997). With quality of life being the main consideration (Arkell, 1993; Glare, 1994), aggressive interventions may need to be abandoned in favour of more traditional palliative care practice.

PLWHA may request assistance with ending their life in the terminal, phase of their illness (Scott & Irvine, 1997). These clients often decline offers of supportive counselling or hospitalisation and in these cases, it is recommended the client undergo a psychiatric assessment and the health care worker discuss the issue with a colleague. While it is illegal to assist clients to end their life in the State of NSW, Burich and Judd (1997) state if the client has insight into their decision, is not influenced by a psychiatric illness, is assessed as competent and management options have

been explored, the health care worker is not entitled to interfere with their decision.

2.8.2 Discharge Planning of PLWHA

It is the role of the discharge planner to assess the degree of motivation and support the client requires to attain independence and self care on discharge from hospital. Assessment is made through an open relationship between the discharge planner and the client and their relatives (Delaney et al., 1994). Initiating discharge planning early in the hospitalisation can enhance the utilisation of existing resources (Sharp et al., 1991).

It is preferable that clients choose their health care setting and their place of death. In some cases, however, home will not be possible due to homelessness, social problems (Arkell, 1993), diagnosis (for example, dementia) and lack of a carer making home an unsafe option (Schmidt, 1992). McCormick et al. (1991) interviewed PLWHA and identified that, although most preferred home care, issues that they found important when considering long term care included the availability of emotional and medical support and privacy.

The discharge planner coordinates discharge as part of the multidisciplinary team (Delaney et al., 1994). The establishment of a network between the hospital and community based service providers, with the consent of the client, can move the focus of care from the hospital to the community and this can be empowering to the client (Lempp, deBoard & Brown, 1994). Effective communication between service providers can prevent a fragmented home care service (Burns-Tisdale, Duprat & Wells, 1994), instill clients with a greater sense of independence and enable the provision of highly comprehensive and individualised care (Delaney et al.). Home based therapy, for example, IV medication, is an important aspect of treatment that requires particularly close coordination and communication

between hospital, GP, community nurse, client and carer (Stewart et al. 1997).

In an Australian study of 12 community nurses (Armitage, 1995) most felt that liaison through nurse discharge planners was satisfactory and believed that continuity of care of their clients between the hospital and community setting was achieved in most cases. The community nurses preferred to be kept informed of their client's progress in hospital and felt that with their community knowledge of the client, they could also contribute to the discharge planning process. This study identified that it was preferred discharge planners be nurses, as the information reflected a nursing perspective and acknowledged that direct communication between the hospital and community settings could be difficult to achieve, particularly in cases where hospitals serve large urban areas.

In an American study (Wright et al., 1993) case managers stated the most useful assessment activities in the development of a care plan were the following (in order of usefulness):

- 1) History of the illness/treatment status.
- 2) Economic status/benefits eligibility.
- 3) Physical assessment/systems review.
- 4) Functional assessment.
- 5) Social relationships and support system assessment.
- 6) Personal health and lifestyle habits/substance abuse patterns.
- 7) Physical environment/safety risks.
- 8) Emotional/behavioural responses to illness.
- 9) Clients knowledge level related to disease.
- 10) Current health problems.

These issues are also relevant in Australia. Due to differences in our health care system however, it is unlikely that the client's economic status and its relationship to eligibility for benefits would rate so highly.

2.8.3 The Community Nursing Role in Caring for PLWHA

Identified Australian literature which addresses the community nursing role in caring for PLWHA includes Chalmers et al. (1991) and ACHA, (1991). Although Chalmers et al. focusses mainly on the organisational nursing issues, the ACHA offers a community nursing care plan for people with HIV/AIDS disease. Hurley and Ungvarski (1994) undertook a similar study which is relevant to the research questions of this study (as stated in Section 1.6). Despite this, their sample was based on clients discharged from a home health care service in New York in 1991 and did not include clients receiving hospice care or home infusions. These aspects of their study limit the value of comparisons of the findings from their study with this study which included clients who were being palliated and/or received intravenous treatment at home.

The community nurse is required to respond to the client's changing needs and is responsible for planning care, implementing actions and the ongoing monitoring of the client and their home situation (Chalmers et al., 1991). While discharge planning does influence the continuity of care, community nurses do their own physical and psychosocial assessment and decision making with regard to client interventions (Armitage, 1995). They are in a perfect position to assess the client's holistic needs in their own home environment in a way that is not possible in the hospital or outpatient setting (Schietinger, 1986). This is also the case for the community nurse's ability to extend their health promotion work beyond the client to their family and carers (Lang, 1993) and the broader community. In addition, emphasis is taken off the sick-role when care is delivered in the home (Widman et al., 1994). The challenge of the community nurse is to become an integrated part of the client's community network (Sowell, 1995) and develop a long-term partnership which affords a unique relationship in which each is able to learn and grow (Bennett, 1988).

Holzemer and Henry (1991) analysed the nursing care plans of four agencies in the San Francisco Bay area and found there were only two areas common amongst all care plans - nutritional concerns and psychosocial well-being. Conversely, Smith (1991), analysed the literature between 1982 and 1991 related to the nursing care of the hospitalised client with HIV/AIDS and identified nine of the most commonly stated problems. Five were physiological, being inadequate nutrition, respiratory problems, impaired skin integrity, diarrhoea and potential for infection. The remaining four problems were cognitive, being altered thought processes, potential for injury, social isolation and a combination of physiological and cognitive, for example, pain. In addition, Bennett (1988) included roles and relationships, and home maintenance as problem areas. Salyer et al. (1987), found the most common nursing diagnoses included the potential for infection, nutritional deficit, alterations in oral mucous membranes, fluid volume deficit, impairment of skin integrity, alteration in bowel elimination, impairment of urinary elimination, activity intolerance, impaired physical mobility, impaired gas exchange, pain and cognitive impairment.

The home health care needs of persons with HIV/AIDS are very broad and extend beyond the physical manifestations of the disease (Ungvarski & Hurley, 1995). There is no instrument that reflects the diverse health care needs of these clients (Berk & Nanda, 1994). Table 2.15 presents an overview of some of the documented needs and issues of PLWHA. They include activities of daily living, medication, education and support. Nursing goals and needs may include: maximising quality of life (Bennett, 1988), providing social support (Langford et al., 1992; Norbeck, 1988), restoration of health, tertiary prevention, self care maintenance, administration of IV medication, providing ongoing assistance, palliative care (Schietinger, 1986), client monitoring, liaison with doctors and evaluation of services (Schmidt, 1992). The role of the nurse includes that

of advocate, case manager, health educator, program planner, coordinator and policy advocate (Kuehnert, 1991).

The community nurse requires knowledge of the manifestations of HIV/AIDS to effectively casemanage and respond to the complex needs of PLWHA (Berk & Nanda, 1994). For example, the nursing goals of clients with haematological disorders (Section 2.5.1.6) include assessment, planning and implementing interventions, and client education to prevent or minimise the complications (Ownby, 1995). This approach is appropriate for most disorders in immunocompromised clients.

It is vital that community nurses recognise the possible implications of symptoms that are acute and specific, for example those consistent with lymphoma (Section 2.5.1.7), and encourage and assist their clients to seek medical assessment as soon as possible. It is important that community nurses with clients experiencing peripheral neuropathy (Section 2.5.1.8) assess the client's antiretroviral medication, response to treatment and emotional status. Clients who are severely immunocompromised should be encouraged to attend periodic ophthalmology appointments to be screened for CMV retinitis (Section 2.5.1.9). It is recommended that community nurses check their clients' physical and mental status each visit (ACHA, 1991).

Table 2.15 The Documented Activities, Needs and Issues of PLWHA in the Home

Activity/Need/Issue	Reference
Activity of Daily Living Assessment: 95% cleaning and laundry, 93% shopping, 80% medication, 54% bathing and treatments.	Hurley & Ungvarski, 1994 USA (n=244)
Services of a Home Health Care Agency: 73% nursing, home aide 52% (mainly light housekeeping, shopping and toileting) physical therapy 15%, mental health 12%, pharmacy card 6%.	Foley, Fahs, Eisenhandler & Hyer 1995 USA (n=52)
Case management problems of a Visiting Nursing Service: Client/Significant Others, Housing/Community, Support Services and Nurses needs.	Schmidt 1986 USA (n=100)
Initial home visits by hospital nurses: Education and support 23% (mainly treatment and medication), informal carer issues 33%, acceptance of illness 32%.	Moons, Kerkstra & Biwenga 1994 Amsterdam (n=13)
Client Problem/Need: Anxiety, anger, depression, fear; Alterations in mental state; fatigue and malaise; respiratory distress, dyspnoea; anorexia, nausea, vomiting, diarrhoea; inadequate resistance to infection; fevers; bleeding; alteration in skin integrity; pain; reaction to medication; prevention of injury; substance abuse; legal issues; dying at home.	ACHA, 1991 Australia
Community nursing problems first HIV/AIDS client: Physical care, stigma, lack of knowledge and fear amongst nursing service, families and community, lack of medical experience and support, fears confidentiality and discrimination.	Chalmers, Hartwig, Cook & O'Brien 1991 Australia

The community nurse is in a prime position to educate clients about preventative strategies that can be implemented in their home environment, for example the handling of cat excrement to reduce the risk of developing cerebral toxoplasmosis (Lander & Reid, 1991) (Section 2.5.1.8). The community nurse also requires the skills to administer therapies in the home (Section 2.5.1.3). Due to the importance of LTVADs for intravenous medication delivery and the resultant discomfort to the client infection causes, it is important that community nurses maintain strict aseptic technique when attending the access site. Community nurses need to educate clients and carers as to how they can minimise their potential to develop bacterial infections. Furthermore, community nurses need to be knowledgeable of the early signs and symptoms of infection so immediate steps can be taken to assess the client in the early stages of infection.

The assessment and monitoring by health care workers of the psychosocial (Section 2.6) and psychiatric aspects (Section 2.5.2) of clients is imperative if HIV is to be thoroughly managed (Perkins et al., 1993). Recognition of the impact personality disorder can have on coping with HIV, maintaining relationships with health care workers and adherence to therapeutic interventions is important in the planning of sensitive and effective holistic care (Perkins et al.) by community nurses.

PLWHA who may be more at risk of recurrence or exacerbation of previously diagnosed psychiatric conditions when confronted with the progression of HIV illness may be identified through a detailed medical history (O'Dowd, 1995). As clients with HIV who develop acute psychiatric disorders require both medical and psychiatric assessment (Miller & Riccio, 1990), it is recommended that palliative care services and caregivers work collaboratively with mental health services to meet their

needs (Glare & Cooney, 1997; Grassi et al., 1995). Community nurses may choose to co-casemanage the client with a community mental health nurse.

It is important that community nurses recognise the decision making limitations of their clients when they are experiencing acute psychiatric episodes and advocate on their behalf as required. The community nurse may be the first health care worker to identify an existing risk of suicide and should liaise with other members of the multidisciplinary team for further comprehensive assessment and management plans. PLWHA who have a severe or acute psychiatric disorder may need to be considered for an involuntary admission so as not to jeopardise the health of themselves or others (Miller & Riccio, 1990). While treatment strategies will be reliant upon the psychiatric condition and its causes (Catalan, 1995), it is important that delivery of mental health services be appropriate to the varying sociodemographic responses to stress (Fleisham & Fogel, 1994).

As most people with HIV in Australia are homosexual men and/or IDUs (Scott & Irvine, 1997; NCHECR, 2000b), it is important for the community nurse to understand how the lifestyles of their clients impact upon their health. Nurses may be able to assist PLWHA respond to discrimination by offering interventions that maximise their coping abilities, for example, emotional support, counselling and education (Cameron & Crisham, 1994). IDUs may have periods of relative stability alternating with chaotic episodes when their drug use is out of control (Wodak & van Beek, 1997), making the provision of nursing care more challenging (Carnegie & Rutter, 1992).

Manifestations of HIV/AIDS, for example neurological symptoms, often lead PLWHA to experience fear and shame (Schietinger, 1986), and require emotional support by their community nurse. Those providing psychoemotional support to PLWHA, their partners and relatives also need to have an understanding of the physical effects of the disease and its treatments to maximise the effectiveness of their interventions (Catalan, 1995). With improvements in treatments and length of survival, there is an even greater need to assist clients improve their quality of life, coping skills and adjustment ability (Kelly et al. 1993).

Relatives, spouses and partners of clients are reliable sources of knowledge for the community nurses, assisting them to familiarise themselves with and assess the individual aspects and broad needs of their client (Berk & Nanda, 1994). Community nurses depend heavily on the resources of these family and friends to enable the client with advanced illness to remain at home (Salyer et al., 1987).

Schietinger (1986) stated that while the assessment of the needs of the HIV/AIDS client is simple, resolving the problems is the challenge. Effective home management of PLWHA requires collaboration between various health care workers (Bennett, 1988; Chalmers et al., 1991; Layzell & McCarthy, 1992; Moons et al., 1994); access to a knowledgeable local doctor (Stewart, 1997); ongoing skills and knowledge to ensure expert care is offered; the development of trust between health care workers, the client and their family (Snee, 1994); and commitment, creativity and compassion (Bennett). Integrated models of nursing encompass physical as well as spiritual needs (Bennett; Meeks-Festa et al., 1994) and support and counselling are also important aspects of nursing care (Moons et al.).

Community nurses are required to liaise with the client and others through regular meetings and telephone conversations to review and respond to the

client's changing needs (Chalmers et al., 1991). In most cases, planning will be required not only for the client but also for their close support network, and the community nurse may also have to deal with the client's community (Ungvarski et al., 1994). It is vital that the client's wishes are incorporated into the care plan. In a study undertaken in Melbourne, Australia, Kermode (1995) identified that hospitalised clients (n=8) found nursing interventions motivated by care to be most helpful, particularly with those promoting their security and comfort. Of the varying models of community nursing care, an English study of 77 nurses stated clients usually preferred a specialist HIV/AIDS nursing team to care for them (Layzell & McCarthy, 1993).

The importance of promoting available services was emphasised in an English study (Petrou et al., 1996) which found that the identified unmet needs of PLWHA were mainly due to poor understanding in this area. Evaluation of nursing interventions is important, and in their advocacy role, nurses need to ensure that they are not only focussed on the economic factors of service provision (Sowell, 1995). Although it is unlikely that we will have definitive methods for the prevention and treatment of HIV/AIDS for some time to come, medical and nursing staff maintain an important role in the management of chronic disease (Krause, 1993).

Nursing PLWHA can be more stressful and time consuming than caring for other clients (Chalmers et al., 1991; Slone & Stephany, 1995; Swan, Benjamin & Brown, 1992). Community nursing of PLWHA can be particularly stressful as these nurses work autonomously without the formal and informal support at hand in the hospital setting (Schmidt, 1992) and additional supports maybe be required in the home (Halloran, Corless & Belyea, 1994). A good support network is required as morale can be affected when there is no response to interventions for multiple problems (Carnegie & Rutter, 1992). Nurses themselves need support and

caring (Gilyard Brewington, 1994). Community nurses require support in their professional development so they can acquire the knowledge that allows them to practice effectively (Moons et al., 1994). Topics for education should include transmission, prevention, review of beliefs, attitudes, feelings about issues related to HIV/AIDS (Spence, Laschinger, Goldenberg & Dal Bello, 1995) and medications and treatments, including access to experimental and complementary therapies (Schmidt, 1992).

Carers of PLWHA may be subjected to the stigma experienced by PLWHA and health care workers may be strongly influenced by their family members and friends. Staff education may assist reservations that nurses may have about caring for PLWHA but may not eradicate their anxieties about the unpredictability of the disease. Strategies should be explored and implemented to address the occupational stress experienced by community nurses caring for PLWHA (Carney, 1990).

2.9 Conclusion to Literature Review

An overview of the literature related to the research questions of the study (Section 1.6) has been provided. The demographic, clinical and psychoemotional aspects of this complex disease have been discussed from a community nursing perspective. Although there is a dearth of Australian literature, variables can be identified in many cases from overseas experiences. However, these are of limited value in comparison with the Australian experience of PLWHA.

Despite a decreased incidence of HIV/AIDS and deaths following AIDS since the study period, the AIDS crisis is not over. There remains a need to focus issues related to prevention, treatment and care. PLWHA experience a wide and complex range of physiologic, psychosocial and psychoemotional consequences as a result of HIV. The effects of HIV also impacts on their family, friends and the broader community. There is still

much to learn about the nursing care of these clients, particularly those with advanced disease.

CHAPTER 3

METHODOLOGY

3.1 Introduction

In this chapter the choice of study design including the setting, sample, data collection technique and methods of data analyses are clarified and the ethical considerations outlined. The rationale supporting these choices is included to provide the reader with the background knowledge necessary to understand the study. The literature related to the research methodology used in the study is reviewed. In addition, problems and issues experienced by the researcher and their management are addressed.

3.2 Research Design

The data from the study was obtained retrospectively from the content of CNRFs (**Appendix B**) of HIV/AIDS adult clients which were completed within the health care setting. The data provided an accurate record of some events that actually occurred during the clients' illness. It was decided to use a descriptive exploratory method to examine identified variables using quantitative and qualitative analysis. These aspects of the research design will now be discussed.

In retrospective studies, analysis is undertaken of variables or events that have already occurred. The dependent variable has already been affected by the independent variable and in this study the researcher has attempted to link present events with past events. The independent variable has not been manipulated as retrospective studies use a nonexperimental design. In the current study, the independent variables include the CNRFs as well as the assessment and procedure for community nursing referral. The dependent variables include clinical and psychoemotional aspects of clients and the requests of community nurses

documented on the CNRFs by the discharge planner. The retrospective study has been recommended as an efficient methodology to identify the actual types of problems experienced by individuals in the sample, so that nursing needs may be addressed in areas where limited information is available (Hurley & Ungvarski, 1995). A limitation of this design is that, while correlations between variables can be studied, causality cannot be established (Lo Biondo-Wood & Haber, 1990).

Descriptive and exploratory research designs are used to gain insights about a phenomenon (Skodal Wilson, 1989) and these can be used to justify, assess or plan for improvements of conditions (Lo Biondo-Wood & Haber, 1990). Furthermore, the three purposes of exploratory studies are to identify variables from the field situation which may be significant, where possible reveal relationships amongst the variables and lay the foundation for further theory or hypothesis driven studies (Kerlinger, 1986). The retrospective, descriptive exploratory design used was considered appropriate to the purpose and significance of this study (as stated in Section 1.5 and 1.7) which sets out to describe and explore documented information on CNRFs of clients with HIV/AIDS.

A mixed methodology of quantitative and qualitative methods was used. This comprised descriptive statistical analysis and content analysis of identified demographic, clinical and psychoemotional variables. Quantitative methods use the deductive reasoning of statistical analysis, to identify and describe the incidence and relationships of specific variables, including demographic, clinical and psychoemotional data. The psychoemotional status refers to the psychological and emotional states of the clients. Qualitative analysis, which was undertaken without preconceived ideas of outcomes, was used to further explore documented factors related to the psychoemotional status of clients. Many nurse researchers accept both quantitative and qualitative methodologies, and

they are both necessary to expand the body of nursing knowledge (Hurley & Ungvarski, 1995).

3.3 The Research Setting

The study setting where the research data was identified and collected was a nineteen bed HIV/AIDS Unit in Sydney, NSW. The HIV/AIDS Unit admitted adult clients with HIV/AIDS for acute, respite and palliative care. This setting was chosen due to the accessibility of a homogeneous sample, uniform data, and an understanding of the day to day operation and management of the inpatient unit by the researcher.

3.3.1 The Process of Community Nurse Referral of Clients

The discharge planner of the HIV/AIDS Unit was a community based HIV/AIDS Clinical Nurse Consultant who was responsible for the assessment and referral of HIV/AIDS clients to community nursing services. The researcher held the role of discharge planner from May 1991 to March 1997.

The purpose of an initial referral was to introduce the client to the community nurse by giving an overview of relevant details of the client's past history as well as recent events. The purpose of subsequent referrals, also known as re-referrals, is to update the community nurse of events that occurred during the client's hospitalisation and to assist them to prepare and respond to the client's changing needs.

The completion of a CNRF was only part of the overall discharge planning process. Most of the CNRFs were completed by the discharge planner following discussion with the client; a review of their inpatient hospital records; and discussion with the health care team over the period of their hospitalisation. During the study period, the process of assessment and

referral of a client to a community nursing service by the discharge planner followed a consistent format. This included:

- ◆ Client Interview - this was conducted on at least one occasion during the client's hospitalisation. The discharge planner approached the client (and carer as appropriate) and discussion took place regarding issues surrounding the client's concerns and needs on discharge, home management and existing supports. In cases where the client had not previously been referred to a community nursing service, specific information may have been provided by the discharge planner regarding local community nursing services. If the discharge planner considered that community nursing referral was appropriate, the client was offered a referral.
- ◆ Liaison with other health care workers - the discharge planner routinely attended clinical HIV/AIDS Unit based multidisciplinary team meetings where the clinical aspects, psychosocial issues and management strategies of clients were discussed. Further liaison between the discharge planner and the client, carer and ward and community based teams took place as required during the discharge planning phase.
- ◆ Written referral - in cases where community nurse referral was offered and accepted, the discharge planner completed a CNRF using information documented in the client's hospital file and acquired from conversations with the client, carer, and other service providers. Referral was written on or close to the date of the client's discharge or leave from the HIV/AIDS Unit. In addition to variables printed on the form, the discharge planner documented relevant information concerning the client's past and recent clinical history, demographic

aspects, psychosocial aspects, emotional aspects and community nursing needs. The CNRF was recorded in triplicate. The original copy was usually posted to the community nurse caring for the client; the second copy was kept by the discharge planner to facilitate follow up and review of clients; and the third copy was placed in the client's inpatient hospital records where the multidisciplinary team could access it.

- ◆ Phone referral - the discharge planner contacted the Community Health Centre where the community nursing service was based and appropriate details were given as a formal referral was undertaken. Initial referrals of clients were usually required to be directed to the Community Health Centre's intake system. In this case, minimal details would be given to the attendant so a personal file for the client could be established. The discharge planner requested that the community nurse serving the geographical area where the client resided make contact for additional information. When the client was a current client of the community nursing service, the discharge planner would communicate directly with the community nurse caring for the client in order to discuss relevant information concerning the client.
- ◆ In some cases, community nurses may have attended the HIV/AIDS Unit to monitor the progress of their client or to receive training for a procedure to be carried out in the home following discharge, for example, the administration of IV therapy.
- ◆ Ongoing liaison - the discharge planner remained available to the client, their community nurse and other service providers to ensure

ongoing communication was facilitated and problems anticipated and prevented as far as possible.

3.4 The Sample

The study used a convenience sample consisting of data collected from 171 CNRFs. These were completed by the nurse discharge planner (who was also the study author) of the HIV/AIDS Unit and were a major part of the process of referring inpatients to community nursing services at the time of discharge (Section 3.3.1). The CNRF was the standard form used in all areas of the hospital at the time of the study. The CNRFs used in this study were a consecutive series of all those completed for 73 clients who were referred to community nursing services from the HIV/AIDS Unit and died between 1st June, 1993 and 1st June, 1995. There is a significant risk of selection bias when convenience sampling is adopted (Lo Biondo-Wood & Haber, 1990). This is due to the non-inclusion in the study of participants who meet the criteria. To deal with this problem, the inclusion criteria ensured all clients who were referred to community nursing services and died within the time frame of the study were included in the sample to overcome the problem of selection bias. In addition to data from the CNRFs, the date of death of each client was included in the study.

Of the 73 clients, 49 were first referred to the specific community nursing service from the HIV/AIDS Unit during the study period. For the purpose of the study, the first referral of these clients was designated the initial referral. All of the remaining 24 clients had been referred to community nursing services prior to the study period and had incomplete information on their CNRF concerning some aspects of their past medical history or demographic details. It was postulated that the incomplete information was contained on previous referrals (prior to the study period) and not repeated by the discharge planner on subsequent referrals due to the familiarity of the community nurse with these clients. For 17 of the 24

clients, these specific details were accessed from an additional 31 CNRFs written by the discharge planner prior to the study period and included in the study. Previous referrals of the remaining seven clients were not located, possibly because they had been generated from a source other than the HIV/AIDS Unit (Figure 3.1).

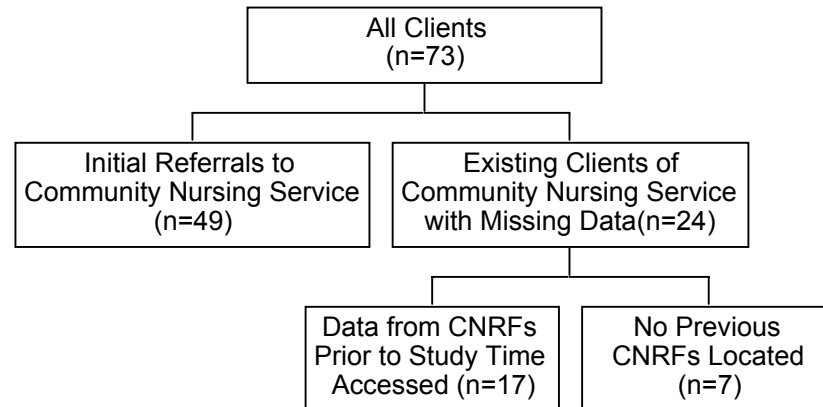


Figure 3.1 An Overview of The Sample Displaying Clients who were Initial Referrals and Clients With Missing Data
CNRFs = Community Nursing Referral Forms

Of the 73 clients in the sample, 29 were referred only once to community nursing services within the time frame of the study. The remaining 44 clients had more than one referral, returning to the HIV/AIDS Unit and being rereferred up to seven more times (Table 3.1). Referrals were labelled from referral 1 up to referral 8. This brought the total of referrals amongst the 73 clients to 171. To clarify, referral 1 was the initial referral for only 49 clients. The initial referral for the remaining 24 clients either occurred prior to the study period or was generated from a source other than the HIV/AIDS Unit. The final sample in this study comprised 188 Data Collection Forms; one for each of the 171 CNRFs completed by the

discharge planner within the study period, and 17 for additional data of the 17 clients within the sample whose CNRFs had missing data. The components of the sample are presented in Figure 3.2.

**Table 3.1 The Number of Times Clients Were Referred to
Community Nursing Services During the Study Period**

Number of Referrals (n=171)	Number of Clients (n=73)
1	30
2	22
3	7
4	7
5	1
6	2
7	1
8	3

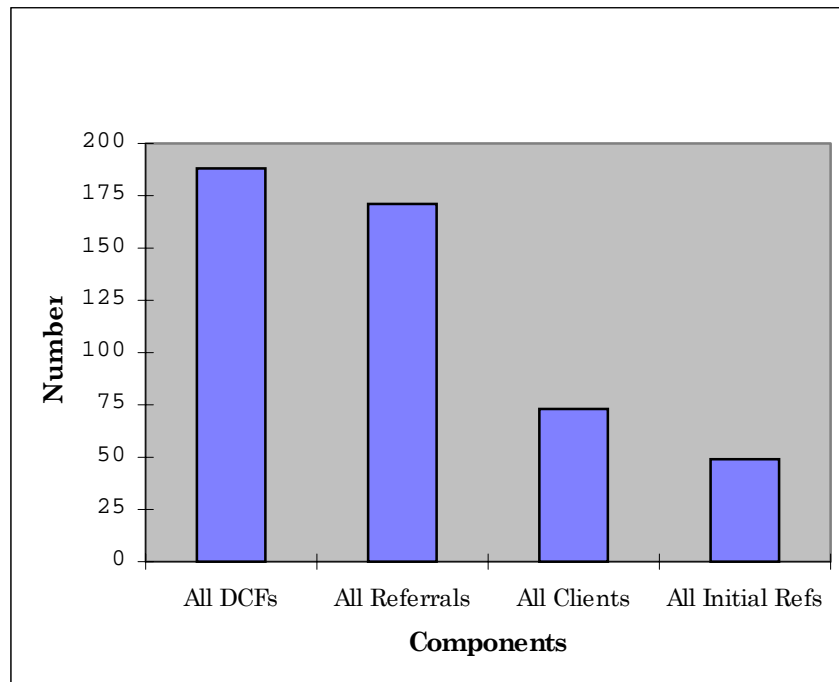


Figure 3.2 The Composition of the Sample DCFs = Data Collection

Forms n=188, All Referrals n=171, All Clients n=73, All Initial Referrals n=49.

Data Collection

3.5.1 Instrument Development

Three instruments were developed by the researcher to facilitate accurate data collection:

- a) Data Collection Form (**Appendix C**).
- b) Data Collection Form Guide (**Appendix D**).
- c) Comments Made During Data Collection Form (**Appendix E**).

The design of the Data Collection Form (DCF) was based on information documented in the CNRFs and was created for the purpose of collecting and reviewing deidentified raw data for the study. It consisted of three sections based broadly on the client's clinical aspects (Section 1), the requests made of community nurses and the abilities of the client

(Section 2), and the demographic aspects in addition to other specific comments (Section 3). The purpose of the Specific Comment section (3u) of the DCF was to document the qualitative data. The purpose of the Researcher Comment section (3v) was to facilitate the researcher's documentation of written aspects relevant to the data collection process of that particular CNRF. For example, the researcher may have commented that the particular CNRF was difficult to read in some places or that the particular CNRF was written by a person relieving the discharge planner.

Due to the vast amount of data collected, it was necessary to create or adapt existing coding systems for specific variables. Many of the variables were coded (for example, past HIV Category B or C diagnoses, allergies, signs and symptoms, and psychoemotional status) to maintain confidentiality and to aid in the process of data collection and data entry into an electronic spreadsheet. The Data Collection Form Guide (DCFG) was created by the researcher to document the codes used in this study. On development of the DCFG, all possible responses were identified for the following variables: Area Health Service of referral (2a), Sex (3d), 'Living with' status (3j) and Contact person relationship (3k). These were coded by the researcher prior to the commencement of data collection. Existing specific codes and categories were adapted for use in the study for some variables. Codes used for HIV related conditions (1f and 1m) were those from the Clinical Trials Team of the HIV/AIDS Unit (**Appendix F**). Codes used for clients nationality (3b) and language (3c) were adapted from the Draft Interim Minimum Data Set for Palliative Care (NSW Department of Health, 1995).

All other codes used in this study were created by the researcher during data collection and were based on specific variables that appeared in the CNRFs. Similar variables, for example describing the clients' signs and symptoms (1j) and psychoemotional aspects (1l), were grouped under the

same code where this was considered appropriate. The variables comprised the actual word(s) used in the raw data. Separate coding systems were created for some variables by the researcher to minimise the risk of error occurring during data collection and data entry. For example, a numerical coding system was used for signs and symptoms and an alphabetical coding system was used for non-HIV Category B or C illnesses. This system facilitates recognition by the researcher of inconsistencies throughout the data collection and data entry process.

A Comments During Data Collection Form (CDDCF) was created for informal note keeping by the researcher. Its purpose was to further clarify and assist the researcher to maintain consistent methods of data collection and coding throughout the sample. It also clarified some limitations of the coding and data collection process.

3.5.1.1 Piloting of the Instruments

Prior to commencement of the study, the DCF, DCFG and CDDCF were developed by the researcher and refined as they were piloted on 48 referrals for 15 HIV/AIDS clients. An early proforma of the DCF is provided in **Appendix G**. During the piloting of the data collection instruments, the researcher established and confirmed a methodical and effective system to accurately collect the research data. During the piloting process, the instruments were further developed and refined to ensure all three were capable of incorporating all of the information and variables documented on the CNRFs. This process of development and piloting has also been used by Hurley and Ungvarski (1994, 1995) in a similar study. The final coding systems used throughout the data collection process were adapted, formulated and confirmed during the piloting process. The need for a CDDCF became apparent during the piloting of the DCF and the DCFG and was created as a direct result of what was learnt during the piloting process.

In addition to the development of the data collection instruments, the piloting process also determined the sample size. This was reviewed as the piloting process revealed the time required for data collection. Following the piloting of the DCF, the initially anticipated sample was reduced by decreasing the time frame of the sampling period from 1st June 1991 - 1st June 1995 to 1st June 1993 - 1st June 1995.

3.5.2 The Data Collection Process

One DCF was used for each of the 171 CNRFs generated within the study period. The data for the 31 CNRFs generated prior to the study period (used for information related to missing data of 17 clients) were recorded onto one additional DCF for each client. These were coded with the client's number followed by 'A' to indicate that the information was generated prior to the study period. The identified missing data was related only to the clients' year of HIV diagnosis, the latest documented CD4 count, past HIV related illness, past non-HIV related illness, past surgery, date of birth, nationality, language, sex, sexuality, pension status and unprescribed substance use. Information relating to each of these variables was included in the additional DCFs only if the data was missing from the CNRFs written within the study time. While it is possible that some variables may have changed with time (for example CD4 count, pension status, substance use), it is expected most would remain unchanged.

Information additional to that found on the CNRFs included the client's date of death, obtained from data and records maintained by the HIV/AIDS Unit and the National AIDS Registry (NCHECR, NSW); and the client's residential postcode (if this was not already documented) to assist analysis of the area the in which the client resided. However, the postcode was not used as the general area of residence was indicated by the Community Health Centre to which the client was referred.

After data collection was completed, the DCFs were reviewed by the researcher to ensure consistent data collection procedures were maintained and any identified errors were corrected. Final minor amendments were made to the wording of the DCF, for example Section 1g), Past other illnesses was changed to Past other diagnoses; and Section 1n), Highlighted ongoing problems was changed to Highlighted ongoing issues. The DCFG and CDDCF were amended accordingly. This process ensured that all forms created to assist data collection followed a consistent format that accurately reflected the data.

3.5.3 Data Entry

The DCF enabled the tabulation of specific variables related to the demographic, clinical and psychoemotional aspects of the clients. Variables from the DCFs were coded and entered into a Microsoft Excel electronic spreadsheet by the researcher. The data was then transferred into a Statistical Package for Social Science (SPSS 8.0), a package for analysing quantitative research data.

3.6 Data Analysis

The findings from the analysis of the content of CNRFs were used to develop a client profile and identify their needs through collection of the following:

- ◆ The demographic aspects of clients.
- ◆ The psychoemotional aspects of clients.
- ◆ The client's symptoms, diagnoses and treatments around the time of hospitalisation and discharge from the HIV/AIDS Unit.
- ◆ Documented requests made of community nurses by the discharge planner of the HIV/AIDS Unit.

3.6.1 Quantitative Analysis

Descriptive statistics were used to organise, summarise and describe the characteristics of the data (Lo Biondo-Wood & Haber, 1990). The most common descriptive statistics used were the frequency distribution, mean and standard deviation. The mean was used as the measure of central tendency, being more stable than the median or mode (Skodal Wilson, 1989) and the sample was large enough for the mean not to be significantly affected by a single extreme score.

The variables analysed quantitatively were the majority of those appearing on the DCFs and DCFG (**Appendix C and D**) apart from Section 3u Specific Comments which were reviewed qualitatively and Section 3v Researcher Comments which did not appear on the CNRFs. While the clients' residential address, post code and telephone number were indicated on the CNRF, these aspects were not analysed by the researcher. To ensure the anonymity of the clients was maintained, only the Area Health Service of the clients' residence was identified.

Descriptive statistics were used to summarise the data in a number of ways:

- a) incidence per client (n=73), indicated the number of clients who experienced the particular variable on at least one occasion within the study period (that is on any CNRF).
- b) incidence per referral 1 (n=73), indicated the number of clients who experienced the particular variable on their first referral within the study period.
- c) incidence per initial referral (n=49), indicated the number of clients who experienced the particular variable on their initial referral to the specific community nursing service.
- d) incidence per total referrals (n=171), indicated how many of the referrals stated that the variable occurred.

The concordance of selected variables in individual clients was compared through cross tabulation and a kappa score was calculated in each case (Fleiss, 1975; Hale & Fleiss, 1993; Norvsis, 1997). The variables selected were the majority of those identified as the most commonly occurring amongst the clients, particularly those known to be clinically related to each other. In addition, the conditions of HIV encephalopathy and cognitive deficit were cross tabulated with some of the psychoemotional variables to which there was a previous suggestion of association (Sections 2.5.1.8 and 2.5.2.1).

3.6.2 Qualitative Analysis

In this section the method used for the qualitative analysis of selected psychoemotional variables is demonstrated. The units of analysis, development of categories, process and rationale of the categorisation process, reliability and validity are explained.

Following exploration of various methods of qualitative analysis, the most commonly occurring psychoemotional variables were identified and explored using content analysis of the Specific Comments section (3u) of the DCFs. Content analysis allows a more complete and detailed analysis of word data than quantitative methods, allowing the findings to reflect the complexity of the subject studied (Scalon, 1991). Duncan (1989) stated that it is “a technique which lies at the crossroads of qualitative and quantitative methods” as it involves the objective and systematic quantitative categorisation of documented data (Skodal Wilson, 1989; Lo Biondo-Wood & Haber, 1990).

Being consistent with semantic content analysis (Skodal Wilson, 1989), the word data was identified and analysed from the Specific Comments Section of the DCFs (3u) only if it was documented as being directly related to the identified variable. The semantic content analysis simply involved the

coding and counting of various aspects of documented data. This method was chosen because of its higher level of validity compared to inferred content analysis in addition to the time constraints of the study.

The qualitative process used in the study to analyse the data, adapted from that described by Duncan (1989) was as follows:

- 1) The most commonly occurring psychoemotional variables were identified.
- 2) Each comment specifically related to each identified psychoemotional variable was identified and documented using a verbatim process.
- 3) Each comment was counted and then coded and developed into relevant categories.
- 4) The identified categories were reviewed and amended separately for each psychoemotional variable.
- 5) The identified categories of all the psychoemotional variables were compared reviewed and amended to ensure consistency throughout the data.
- 6) Categorisation of the specific comments investigated were repeated and reviewed (steps 4 and 5) three times by the researcher and once by an independent person, in order to ensure reliability.

The content analysis process undertaken by the researcher was guided by the following three steps recommended by Skodal Wilson, (1989): deciding on the unit of analysis, developing the set of categories, and developing the rationale and illustrations to guide the coding of data into categories. These three steps are now discussed in relation to the study.

3.6.2.1 The Units of Analysis, Category Development and Coding of Data

Of the total incidences of the clients' psychoemotional status (n=167) amongst all referrals (n=171), those occurring in five (3%) or more referrals were identified. The comments were identified for each psychoemotional variable to which they directly related and were counted (n=12 variables; incidence range from 5-31) and reviewed. Due to the modest level of additional informative data, the prominence of the most commonly occurring variables in the literature, and the time constraints of the study; the researcher reduced the sample to be analysed and reported. The psychoemotional variables which occurred in thirteen (8%) referrals or more (n=4 variables; incidence range 17-31) were examined. They were despondent/depressed mood; distress/stress/anxiety; grief issues and 'non-compliant/uncooperative'. The units of analysis were the Specific Comments section of the DCFs that directly referred to these variables.

Each of these steps was taken by the researcher to address the challenges of reliability and validity perceived by critics to be related with content analysis (Skodal Wilson, 1989). In this study, reliability refers to the consistency of identified categories on independent assessment and validity refers to the accuracy of the categorisation procedure in exploring the variable (Scanlon, 1991). It was considered important that the researcher demonstrate that the categories met the criteria of homogeneity, inclusiveness, usefulness, mutual exclusiveness, clarity and specificity (Skodal Wilson). The rigorous review of categories involved the clarification and development of a rationale for the categorisation process; the clear definition of categories; demonstration of how the categories reflected the data and how the data was coded into specific categories; and that the categories were relevant to the research question.

Each of the four selected psychoemotional variables was examined individually. The set of categories was developed following intense critical review and reflection of the content of the specific comments related to the identified variables. The categories were defined and reviewed by the researcher to ensure they represented all the content of the specific comments analysed; were relevant and related exclusively to those aspects they encompassed; were consistent throughout all the psychoemotional variables examined; and were relevant to the third research question (Section 1.6). The categories were further examined and grouped into specific categories and broad categories. The broad categories represented the major themes of the psychoemotional variable (for example the physical effects of HIV/AIDS illness) and the specific categories represented minor themes of the broad category (for example signs and symptoms, results of clinical investigations, and reduced ability).

Once finalised, the process of categorisation was clearly elucidated to allow objective assessment of the coding system to be undertaken. The categories were well defined by their title and the findings were presented clearly for each psychoemotional variable. An independent and objective researcher who assessed the coding procedure to ensure the reliability and validity of the categorisation of the data duplicated the findings. Eight broad categories, each with related specific categories, were identified (Section 4.5.1.2).

3.7 Ethical Considerations

Written ethical approval to conduct this study was granted in 1995 by the Australian Catholic University Research Projects Ethics Committee (**Appendix H**), and the South Eastern Sydney Area Health Service HIV Research Group, Nursing Research Committee (**Appendix I**) and Ethics Committee (**Appendix J**). However, this was a lengthy process that required 3 resubmissions to the Australian Catholic University, their main

concerns relating to the issues surrounding the consent to use the research data. The other major ethical considerations in the study were the confidentiality of the research data and the duality of roles held by the researcher held as discharge planner of the HIV/AIDS Unit. These ethical issues will now be further explored.

3.7.1 Consent

There were no participants in this project, as the sample comprised data extracted from the CNRFs. It was not possible to seek the consent of the previously referred clients of the HIV/AIDS Unit, as they were all deceased when the study commenced. The need for consent from the clients' next of kin was a contentious issue within the Australian Catholic University's Research Projects Ethics Committee (RPEC), requiring a five month period of clarification, resubmission and interview of the researcher before ethics clearance was granted without this stipulation. Acknowledging their lack of experience in HIV/AIDS research, the RPEC allowed themselves to be guided by and accepted the ethical requirements requested by the Area Health Service Ethics Committee which had significant experience in this area.

Due to issues related to confidentiality of the deceased, and in keeping with Section 17 of the NSW Public Health Act (1991), it was deemed inappropriate to contact the documented next of kin for consent to use the CNRFs as data for this study. It was possible that some were unaware of the HIV status or related conditions or therapies of the deceased. It is also possible that some of the next of kin may still be grieving and contact for consent purposes may cause unnecessary anxiety. Furthermore, some of the next of kin may also have been ill and/or are now deceased themselves. Others may have been uncontactable due to insufficient details recorded on their current address and/or telephone number in the contact person's

details section of the CNRF or because they had changed address since the study time.

The Surveillance Section, AIDS/Infectious Diseases Branch of the NSW Department of Health granted permission for the release of information from the National HIV Registry of Deaths (**Appendix K**). This was used by the researcher to confirm the following:

- ◆ The CNRFs used in this study was in fact those of previous clients who were known to have died within the study time.
- ◆ The recorded date of death.

Permission to undertake the study was sought and granted by the Research Projects Ethics Committee of the Australian Catholic University on 22nd August, 1995. As part of the research application process to the Area Health Service, permission to proceed was sought and granted from the:

- a) Authority governing the use of medical records of the hospital where the HIV/AIDS Unit was located to use the content of CNRFs as data for this study.
- b) Nursing Unit Manager of the HIV/AIDS Unit.
- c) Nursing Unit Manager/Team Leader of Generalist Team of the Community Health Centre where the researcher was based.
- d) Assistant Director of Nursing of the community health organisation the researcher was employed by.
- e) Area Health Service Director of Nursing.

Permission to undertake the study was sought and granted by the Area Health Service:

- a) HIV Research Group - (accepted on 9th August, 1995).
- b) Nursing Research Committee - (accepted on 23rd August, 1995).
- c) Research Ethics Committee - (accepted on 26th September, 1995).

The Australian Catholic University Research and Projects Ethics Committee and the Area Health Service Research Ethics Committee were informed when the sample was decreased from all CNRFs of clients of the HIV/AIDS Unit who died between June, 1991 and June, 1995 (160 clients) to those who died between June, 1993 and June, 1995 (73 clients). The consent given to access CNRFs from the originally anticipated study time allowed the researcher to access CNRFs previous to June 1993 to collect missing data. Progress Reports were submitted by the researcher as required and requests for the extension of the project to December, 2000 were granted.

3.7.2 Confidentiality of Data

The DCFs were allocated a code number but were otherwise unidentifiable to the researcher. In keeping with Section 17 of the NSW Public Health Act (1991) no names were included on any research data. Client codes were kept in a locked cupboard and were not accessible to any other person apart from the researcher. Data was entered on one computer only and access by a password known only to the researcher was used. The purpose of this was to ensure confidentiality by preventing access to the program and protecting the research data files.

The researcher destroyed inconsequential data identified during the course of the study by electronically deleting information from the computer's hard drive and/or floppy disks, or by shredding the hard copies using the facilities of the Area Health Service. The stored research data will remain in a locked filing cabinet for a minimum of five years and destroyed as appropriate by the researcher in the same manner as the inconsequential data.

3.7.3 Dual Roles Experienced by the Researcher

The dual roles held by the nurse as discharge planner and researcher posed particular challenges that needed to be acknowledged and addressed to ensure that the study was undertaken in an objective and ethical manner. The researcher was employed in the discharge planning role in the HIV/AIDS Unit during the study period and was the person responsible for writing the majority of the CNRFs. The researcher, as the discharge planner, was familiar with most clients admitted to the HIV/AIDS Unit and their personal history in addition to the data documented on the CNRFs. As the researcher had access to the CNRFs in her role of discharge planner during the study time, it was considered appropriate by those bodies and individuals who granted permission for the study to be undertaken that she deidentify (that is remove information that specifically identified the client) the data to be used for the purpose of the study.

Problems encountered by the researcher whilst holding the dual role of researcher and discharge planner were:

- ◆ As discharge planner, access to the data was solely for clinical purposes. Permission to access the data for the purpose of research needed to be sought, independent of the clinical role. The access and use of the data for the purpose of this study and issues related to consent and confidentiality were subject to at least the same standard of ethical consideration and scrutiny. The researcher undertook the study in the same way required of an independent researcher.
- ◆ The discharge planner was acquainted with most of the clients in the study. Data was not reviewed by the researcher in the context of what was known about the specific individual client. The researcher used only data documented on the CNRFs. Additional information about any individual client, their family or community nursing care did not

form part of the analysis or interpretation of the data. The possibility of the researcher relating data back to individuals and their particular circumstances was minimised by the size of the sample, the de-identification of the data at the beginning of the study through the removal of names and use of coding systems, the large amount of data generated, the use of the DCFs as raw data and the use of a statistical spreadsheet.

3.8 Limitations of the Methodology

Despite the fact that most research studies use a nonprobability method of sampling due to ease of attainment, it is considered less rigorous and accurate than probability methods (Lo Biondo-Wood & Haber, 1990). Due to the nonprobability retrospective convenience sampling method used in this study, the findings cannot be generalised to the population (Skodal Wilson, 1990), therefore the external validity of the this project is limited.

As this study was a retrospective review of the content of CNRFs, the available data was limited to what was documented (apart from the date of death and the client's residential postcode). The written data was no doubt limited by the diligence of the discharge planner. It is possible this may have been inconsistent at times with the client's perceptions. Furthermore, information valuable to the study may have been omitted. For example, in the data analysed, no reference was made to clients who may have been Aboriginal or Torres Strait Islander (ATSI). If there were clients from this background, there was no indication of this on the CNRFs.

As the data was used originally for clinical rather than research purposes, there were no controls incorporated to ensure consistency within the data (Ungvarski & Hurley, 1995). Information, additional to that documented on the CNRF, may have been communicated to the community nurse by the discharge planner verbally during the routine telephone referral or if the community nurse attended the HIV/AIDS Unit. Therefore, it is important to acknowledge that the data does not represent all information provided to the community nurse on referral.

In addition, the referral of the client to a community nurse is only part of the discharge planning process. Additional referrals may have been made to community physiotherapists, occupational therapists or social workers. A medical letter was typically written to the local General Practitioner and referral may also have been made to a Medical Specialist. The details and content of information shared and requests made of those other than community nurses are not included in this study. Therefore, community nursing interventions and treatments referred to in this study are not representative of all interventions and treatments planned for the client on discharge from the HIV/AIDS Unit to the community.

Requests made of the community nurse on referral were made following consultation with the community nursing team and confirmation that they were able to provide the service being requested. Therefore, services unable to be provided by individual community nursing teams were not formally requested on written referrals.

Due to the large amount of data generated by the information on the CNRFs, the scope of the study has been limited to a generalised overview of the identified issues, rather than a comprehensive analysis of each variable identified and examined. An extensive analysis of all the data generated from this study and a discussion of the natural history and

clinical spectrum of HIV/AIDS, it's complications and nursing interventions, is beyond the scope of this thesis. So too, was detailed discussion concerning the changes in the health care system and the management and treatment of HIV/AIDS since the study time, and comparisons of the findings with contemporary issues impacting on PLWHA and community nursing.

During the quantitative analysis, not all of the identified clinical variables were cross tabulated. It is possible there may have been significant relationships between some variables that were not identified.

As semantic content analysis was used, the units of analysis were only those comments directly related to the identified psychoemotional variables. Although more evidence of the study's validity would have been required, it is postulated the use of inferred content analysis (Skodal Wilson, 1989) would have allowed more data to be included as additional specific comments from the DCF could be linked to the identified variables. Furthermore, it was presumed that some clients would have had additional issues that were not analysed in this study as they were not documented on the CNRFs.

As the codes for some variables were created during data collection (for example symptoms and non-HIV category B or C conditions), they were not grouped according to literature or other established or previously used categories. In retrospect, the groups used for symptoms could have been coded in a different way.

3.9 Conclusion to Methods

The research setting facilitated the access to a sample of 171 CNRFs of 73 clients with advanced HIV/AIDS illness who died within the study period. The use of quantitative and qualitative methods of analysis increased the scope and depth of the findings drawn from the data. The research methods used were appropriate to the objectives of the study.

CHAPTER 4

RESULTS

4.1 Introduction

In this chapter, the quantitative and qualitative findings from the study are presented. The quantitative analysis includes the descriptive statistics of the clients' demographic, clinical and psychoemotional aspects; the cross tabulations of the most commonly identified clinical variables experienced by the clients; and the requests of community nurses. The most commonly identified psychoemotional variables of clients are examined further using the qualitative method of content analysis. Refer to Chapter three for an overview of the research methodology used in this study. Refer to Section 3.4 for a description of the sample.

4.2 Client Demographic and Socioeconomic Aspects

4.2.1 Client Demographics

The majority of clients were male (93%) with only 4 females and 1 transgender. On Referral 1, the clients ranged in age from 24.4 years to 69.6 years with a mean age of 40 (Figure 4.1). There was a similar age range when only initial referrals were considered. The clients' most common country of birth was Australia, with 66% being born here (Figure 4.2). The next most common countries represented were New Zealand and England. Other identified countries in order of incidence were Germany, Lebanon, Scotland, Ireland, Indonesia, Vietnam, Fiji, Argentina and Columbia. All clients spoke English, however it could not be determined from the CNRFs if English was the clients' first language or the fluency with which it was spoken.

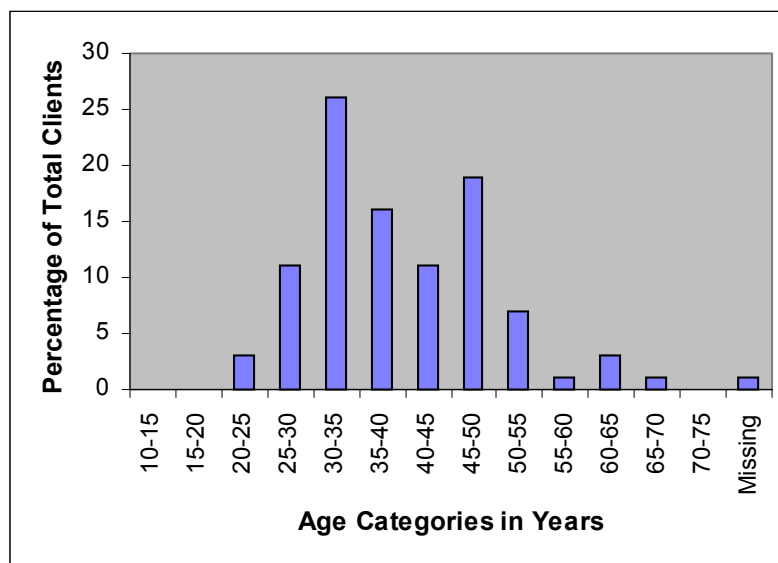


Figure 4.1 The Age of Clients on Referral 1 (n=73). Mean age 40 years with a standard deviation of 9.6.

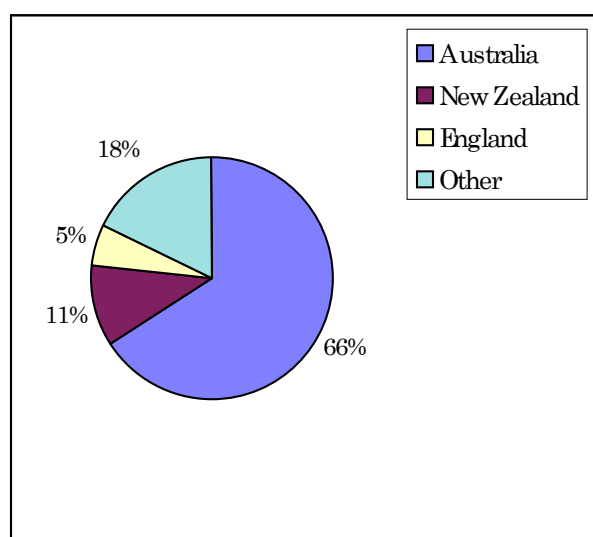


Figure 4.2 The Distribution of Country of Birth of All Clients (n=73).
Other includes Germany, Lebanon, Scotland, Ireland, Indonesia and Vietnam.

4.2.2 The Client's Home Environment and Living Arrangements

The Community Health Centre to which the clients were referred indicated the area health service of the clients' place of residence, at least for the period immediately following discharge from the HIV/AIDS Unit. At the time of Referral 1, the majority of clients (51%), resided within the boundaries of the Eastern Sydney Area Health Service (E.S.A.H.S) (Figure 4.3). The next most common areas of residence were Central Sydney Area Health Service (22%) and Southern Sydney Area Health Service (S.S.A.H.S) (12%). During subsequent referrals only three clients changed their area health service of residence (one from E.S.A.H.S to S.S.A.H.S.; one from Northern Sydney Area Health Service to E.S.A.H.S and one from S.S.A.H.S to E.S.A.H.S and back).

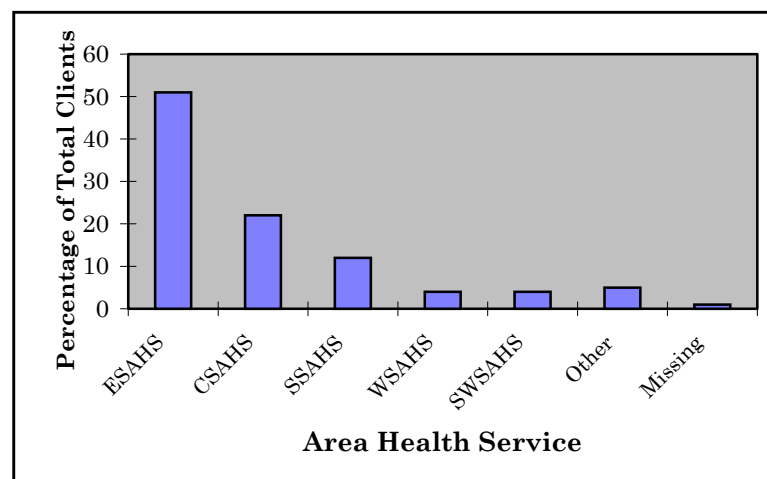


Figure 4.3 The Distribution of Area Health Service on Referral 1 of All Clients (n=73). ESAHS = Eastern Sydney Area Health Service; CSAHS = Central Sydney Area Health Service; SSAHS = Southern Sydney Area Health Service; WSAHS = Western Sydney Area Health Service; and SWSAHS = South Western Sydney Area Health Service.

At the time of Referral 1, the majority of clients (64%) lived with at least one other person. Twenty five percent of clients lived alone and remained living alone throughout subsequent referrals. For the remaining 11% of clients, the CNRFs did not indicate whether they lived alone. At the time of Referral 1, approximately half of all clients were either living with their partner (26%) or by themselves only. Fourteen percent of clients lived with a friend. The relationship of the remaining clients to the people they lived with were parent, flat mate, offspring and sibling (Figure 4.4).

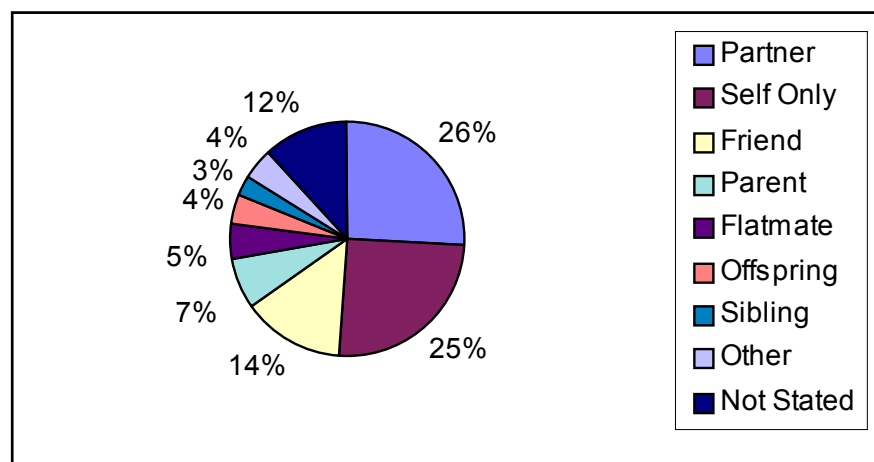


Figure 4.4 Who the Client Lived With on Referral 1 (n=73). In some cases, the person stated as a friend was identified subsequently as a partner.

When all clients are considered, the majority of their relationships with the designated contact person on Referral 1 was a friend (32%), a parent (26%) or a partner (19%) (Figure 4.5). Other contact persons of the client included siblings, offspring and other relatives. For 12% of clients, the friend stated to be the designated contact person or the person or the person the client was living with on Referral 1, was also referred to as a partner of the client on at least one subsequent referral.

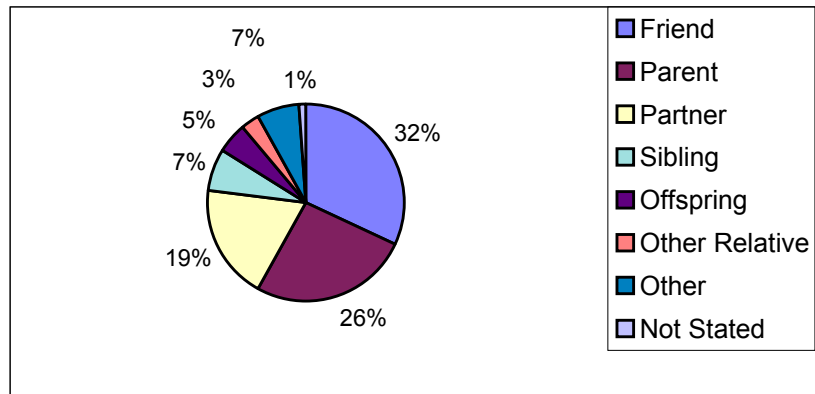


Figure 4.5 The Designated Contact Person of the Client on Referral 1 (n=73). In some cases, the person stated as a friend was identified subsequently as a partner.

On Referral 1, 85% of clients (n=73) had a telephone connected in their home (Figure 4.6). Of the ten clients who did not, four subsequently had one connected. Of the 171 referrals, only 5% were from clients who did not have a telephone.

4.2.3 The Client's Lifestyle

Almost half of all clients (49%) received a pension at some stage during the study period (Figure 4.7). Only 7% were known not to be receiving a pension at any time during the study period and it was not stated whether 44% of clients were on a pension.

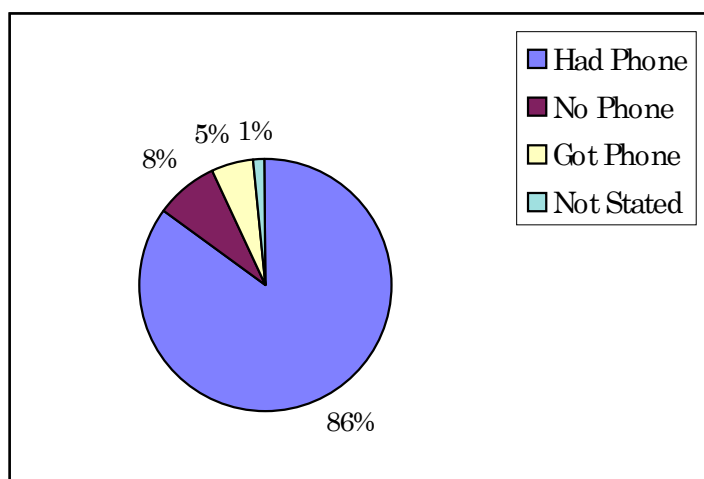


Figure 4.6 The Telephone Status of Clients During the Study Period

(n=73). Had Phone = Had a telephone on Referral 1 and throughout the study period; No Phone = Had no telephone on Referral 1 or throughout the study period; Got Phone = Had a telephone connected at some stage during the study period.

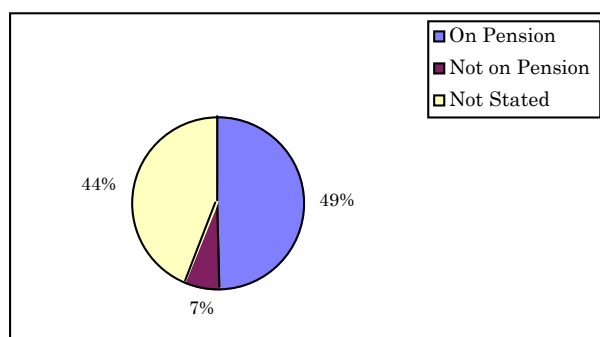


Figure 4.7 The Pension Status of Clients (n=73). On Pension = Clients who were receiving a pension at any stage of the study period.

The sexuality of 29% of clients was stated as homosexual and 3% as bisexual (Figure 4.8). Although the sexuality of 68% of was not specifically stated, almost half (32%) could be deduced to be homosexual due to the gender of the person stated to be the client's partner in at least one CNRF. It could not however, be ruled out that a client was bisexual. Of all clients, 19% could be classified as homosexual or possibly bisexual, 12% as heterosexual or possibly bisexual, and 37% remained unknown. It was deduced that at least half of all clients had homosexual contact at some time (Figure 4.9).

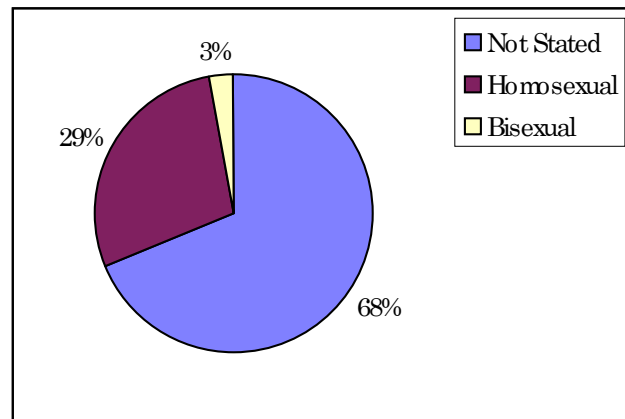


Figure 4.8 The Known Sexuality of Clients (n=73). Not stated means not specifically stated.

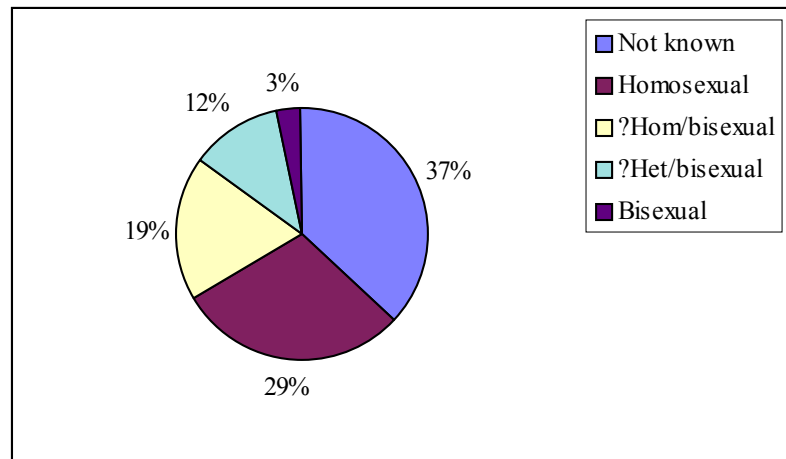


Figure 4.9 The Known and Deduced Sexuality of Clients (n=73).

?Hom/Bi = deduced to be homosexual or bisexual, ?Het/Bi = deduced to be heterosexual or bisexual.

The majority of clients did not have any documented incidence of past or recent substance use (66% and 89% respectively). Past substance use included IDU (16%), ‘heavy’ alcohol intake (11%) and benzodiazepines (3%) (Figure 4.10). The description of alcohol use as ‘heavy’ or ‘social’ was not quantified or explained. Other substances previously used by the clients included heroin, ‘polydrug’ use, ‘drugs’ and nicotine. Only 3% of clients reported the recent use of substances, the most common being cannabis and a ‘heavy’ alcohol intake (Figure 4.10). Other recent substance use included benzodiazepines, injecting drug use, ‘drugs,’ amphetamine, cocaine, morphine and ‘polydrug’ use. Of all clients, 18% were stated to currently use alcohol “socially”, while 14% did not use alcohol at all. Twenty three percent of clients currently smoked cigarettes, and 22% did not smoke. For the majority of clients there was no documentation of social alcohol use (68%) or nicotine (55%) (Figure 4.11).

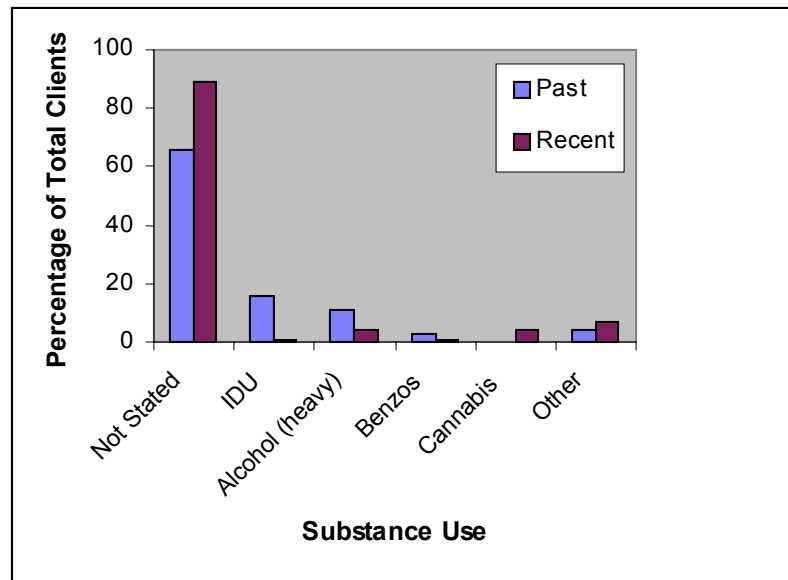


Figure 4.10 Unprescribed Substance Use Amongst all Clients (n=73).

IDU = Injecting Drug Use, Benzos = benzodiazepines. Stated alcohol intake as 'heavy' was not further explained.

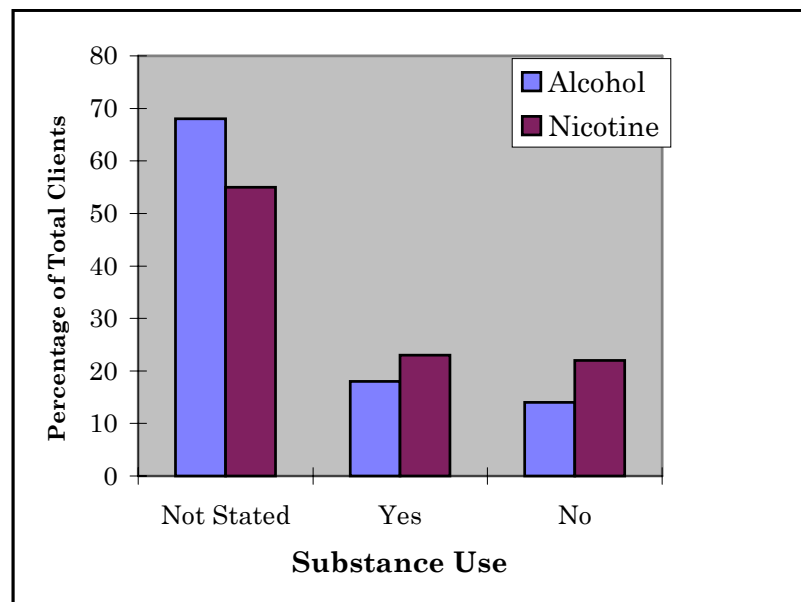


Figure 4.11 The Current 'Social' Alcohol and Nicotine Use of all Clients (n=73).

4.3 The Clinical Aspects of Clients

When the clients' positive HIV antibody status was first diagnosed, they were aged between approximately 14 and 63 years, with a mean age of 34 years and a standard deviation of 10.6 (Figure 4.12). Data was missing for 4 clients. The mean age of clients at death was 40 years, with a range of 24.8 to 69.4 years and a standard deviation of 9.6 (Figure 4.13). The approximate time between HIV antibody diagnosis and initial referral to community nursing services ranged from less than one year to ten years, with a mean of 5 years and a standard deviation of 2.9 (Figure 4.14). There was data missing for 5 clients. The approximate time range between positive HIV antibody diagnosis and death of clients was between less than 1 year and 12 years, with a mean of 6.1 years and a standard deviation of 3.0 (Figure 4.15).

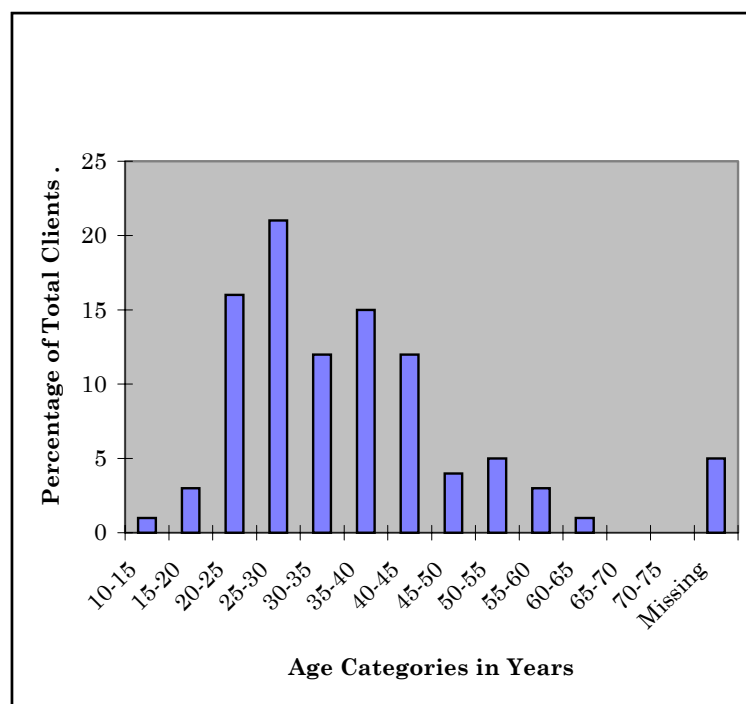


Figure 4.12 The Age at HIV Diagnosis of all Clients (n=73). The mean age was 34 years with a standard deviation of 10.6.

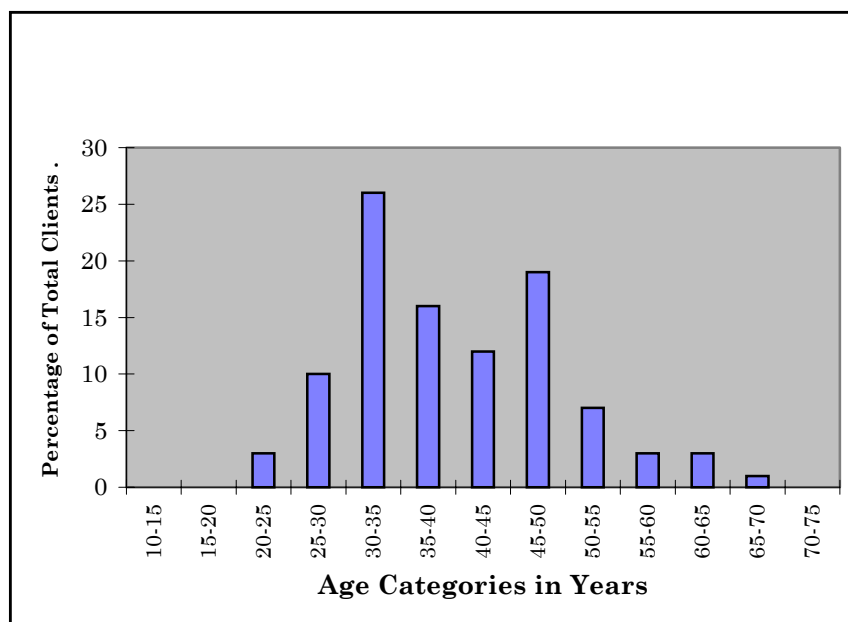


Figure 4.13 The Age at Death of all Clients (n=73). The mean age was 40 years with a standard deviation of 9.6.

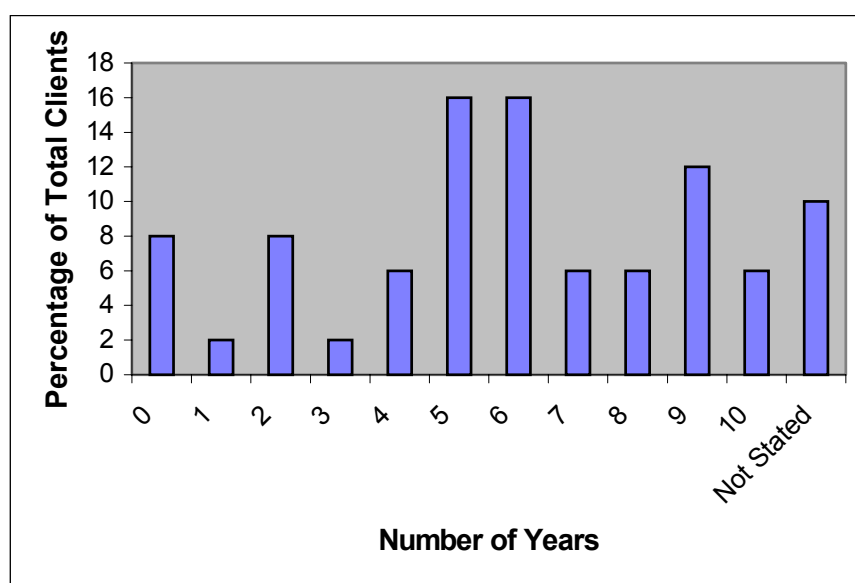


Figure 4.14 The Approximate Time Between HIV Diagnosis and Initial Referral (n=49) The mean time period was 5 years with a standard deviation of 2.9.

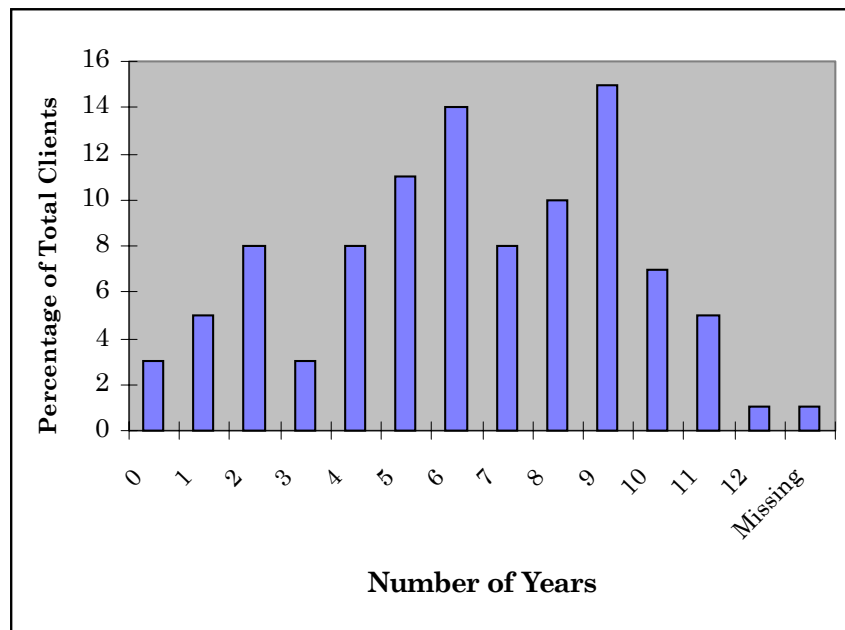


Figure 4.15 The Years Between HIV Diagnosis and Death Amongst all Clients (n=73). The mean length of years was 6.1 with a standard deviation of 3.0.

The first stated CD4 count (Section 2.3.2) on any CNRF for the majority of all clients (68%) was less than 100 cells/mm³, with 52% being less than 50 cells/mm³. Two clients had a CD4 count of over 450 cells/mm³ and the CD4 count was not stated for 25% of clients (Figure 4.16). On initial referral, all clients' CD4 count was less than 190 cells/mm³ with a mean of 44 cells/mm³. The CD4 count of 21% of clients was not stated on initial referral.

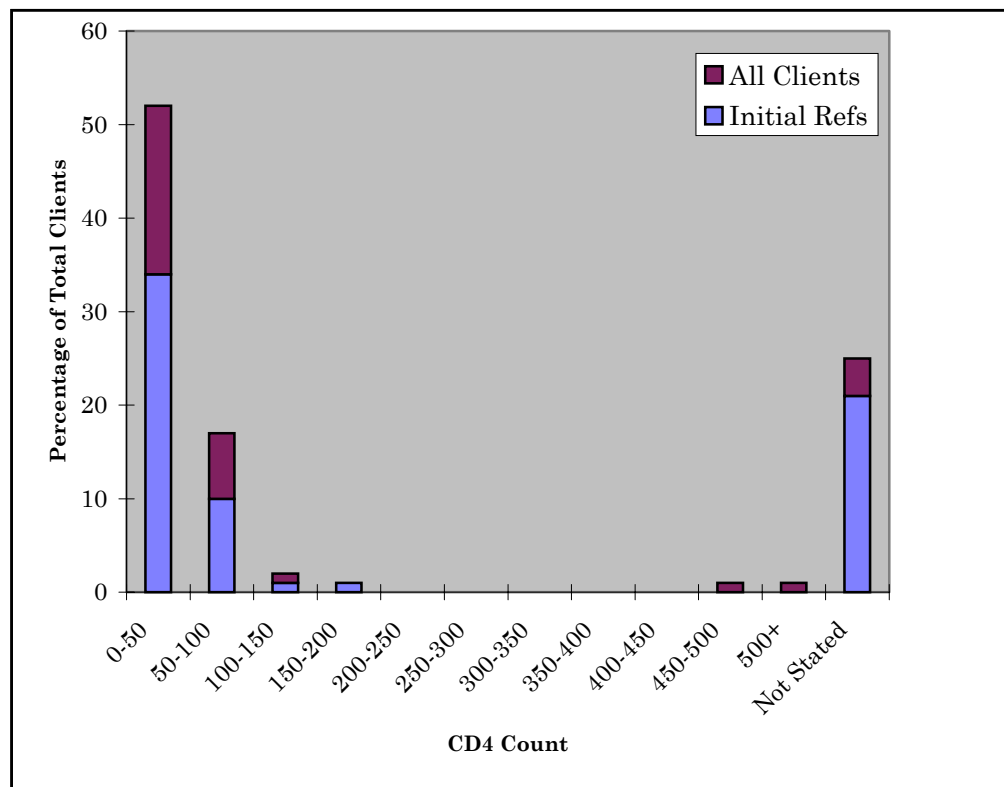


Figure 4.16 The First Stated CD4 Count of All Clients and Initial Referrals Initial Refs = Initial Referrals n=49, All Clients n=73. CD4 Count = cells/mm³.

Fifty one percent of clients (and 39% of all referrals) were documented to have no known drug allergy or intolerance. The drug allergy or intolerance status was not documented for 15% of clients (or 10% of all referrals). The remaining 36% of clients (and 51% of all referrals) were documented to have an allergy or intolerance to medication of which the most common were sulphur drugs (29%), the penicillins (25%) and alphapharm (dapsons) (7%) (Figure 4.17). There were 18 other incidents amongst all clients and 35 other incidents of allergy or intolerance amongst all referrals. These other incidents affected no more than 2 clients per medication and included phenytoin sodium (dilantin), metoclopramide (maxolon) and multiple allergies.

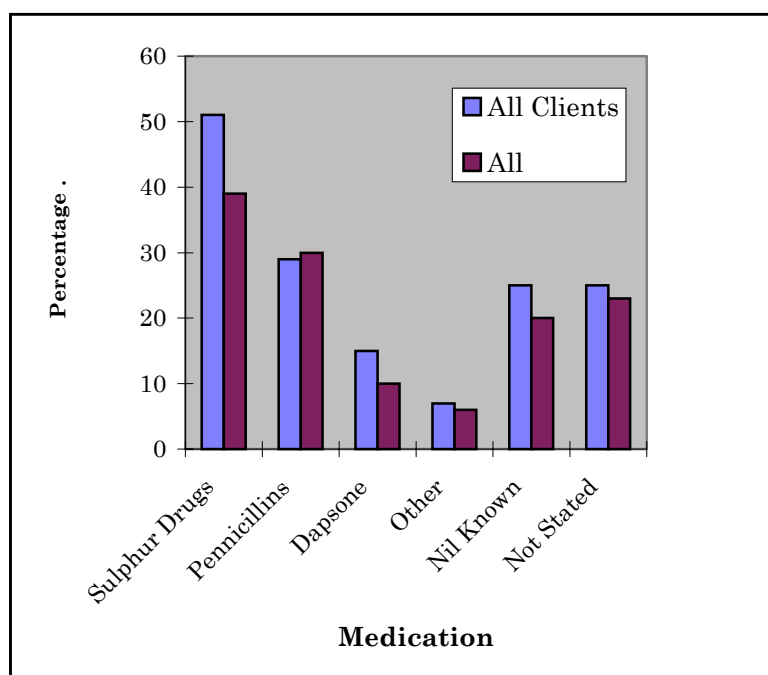


Figure 4.17 The Drug Allergies or Intolerances of All Clients and All Referrals All clients (n=73); All referrals (n=171).

4.3.1 The Clients' Past Clinical History on Referral to Community Nurse

The clients' past history on referral to community nursing services pertains to conditions experienced prior to their current admission, but does not include signs and symptoms they experienced leading up to their current admission. The past history of the clients' clinical aspects are presented on the basis of all clients and initial referrals, in addition to HIV Category.

When all clients were considered (n=73), there was a total of 409 incidents of 102 previously diagnosed conditions on referral. The majority of these (57% of incidents and 77% of conditions) were represented by Non-HIV Category B or C conditions (Table 4.1). When only initial referrals are

considered (n=49), there was a total of 186 incidents of 66 previously diagnosed conditions on referral. The majority of these were also represented by non-HIV Category B or C conditions (60% of incidents and 71% of conditions).

Table 4.1 The Incidence of Conditions Previously Experienced by Clients on Referral by HIV Category

	HIV Category C Conditions		HIV Category B Conditions		Non-HIV Category B or C Conditions		All Conditions	
	Total Conditions Incidents		Total Conditions Incidents		Total Conditions Incidents		Total Conditions Incidents	
All Clients	16	123	7	54	79	232	102	409
Nil Known	7 Clients (10%) had nil known past history of HIV Category C or HIV Category B conditions				0 Clients	0	0 Clients	0
Not Stated	10 Clients (14%)	–	34 Clients (47%)	–	9 Clients (12%)	–	6 Clients (8%)	–
Initial Referrals	14	50	5	25	47	111	66	186
Nil Known	8 Clients (16%) had nil known past history of HIV Category C or HIV Category B conditions				0 Clients	0	0 Clients	0
Not Stated	12 Clients (24%)	–	29 Clients (59%)	–	5 Clients (10%)	–	1 Client (2%)	–

Note. All Clients n = 73; Initial Referrals n = 49.

When all clients are considered, the most common conditions previously experienced by clients on referral to the community nurse were oral candida (42%), PCP (32%) and HSV (27%) (Table 4.2). The next most common conditions were anaemia (23%), hepatitis A, B and/or C and CMV infection excluding retinitis (each 21%) and KS (19%). Other more

Table 4.2 The Clients' Previously Experienced Conditions on Referral

HIV Category	Conditions	All Clients (n=73)	Initial Referrals (n=49)
		Frequency (%)	Frequency (%)
B	Oral Candida	31 (42)	14 (29)
C	PCP	23 (32)	11 (22)
Non B or C	Herpes Simplex	20 (27)	11 (22)
Non B or C	Anaemia	17 (23)	7 (14)
Non B or C	Hepatitis A, B or C	15 (21)	9 (18)
C	CMV Infection	15 (21)	5 (10)
C	Kaposi's Sarcoma	14 (19)	6 (12)
C	MAC	13 (18)	4 (8)
Non B or C	Drug Intolerance	13 (18)	7 (14)
B	Peripheral Neuropathy	12 (16)	7 (14)
Non B or C	Chest Infection	10 (14)	6 (12)
C	Oesophageal Candida	9 (12)	3 (6)
C	Presumptive PCP	8 (11)	3 (6)
C	CMV Retinitis	8 (11)	2 (4)
Non B or C	Depression	8 (11)	4 (8)
Non B or C	Ulcer(s)	7 (10)	4 (8)
Non B or C	Herpes Zoster	7 (10)	2 (4)
B	Microsporidia	6 (8)	2 (4)
Non B or C	Asthma	6 (8)	4 (8)
C	Cryptococcus	5 (7)	4 (8)
Non B or C	Ear Disorder	5 (7)	3 (6)
Non B or C	Fall or Injury	5 (7)	2 (4)
Non B or C	Tuberculosis	5 (7)	1 (2)
Non B or C	Syphilis	5 (7)	2 (4)
C	Cerebral Toxoplasmosis	5 (7)	2 (4)
C	Lymphoma	5 (7)	2 (4)
C	HIV Wasting Syndrome	4 (5)	4 (8)
C	Cryptosporidia	4 (5)	1 (2)
C	Presumptive MAC	4 (5)	3 (6)
C	Recurrent Pneumonia	4 (5)	3 (6)
	Other	116 incidents	48 incidents
	Total	409 incidents	186 incidents
	Nil Known	0 Clients	0 Clients
	Nil Stated	6 Clients (8%)	1 Client (2%)

Note. PCP = Pneumocystis Carinii Pneumonia; CMV = Cytomegalovirus; CMV Infection = excludes CMV retinitis; MAC = Mycobacterium Avium Complex; Cryptococcus = extrapulmonary infection; Ulcer(s) = of undiagnosed or unstated cause; HIV Category B Herpes Zoster = recurrent or multidermatomal infection; OHL = oral hairy leukoplakia; ITP = idiopathic thrombocytopenia purpura.

common previously diagnosed conditions included MAC, drug allergy or intolerance, peripheral neuropathy, chest infection, oesophageal candida, presumptive PCP, CMV retinitis and depression. All other conditions occurred in less than 8 clients (11%). These conditions were also represented amongst the most common past history of clients on initial referral.

4.3.2 Recent Signs and Symptoms of Clients

The identified signs and symptoms were those experienced by the clients leading up to their admission to the HIV/AIDS Unit, during their admission or on referral to community nursing services. Results are presented on the basis of all clients, all referrals and initial referrals. In addition, the most common representing signs and symptoms are identified and the symptom of pain is explored further. Signs and symptoms describing the clients' psychoemotional status have been excluded and are presented in Section 4.5.

When all clients are considered (n=73), there was a total of 784 incidents of 86 signs and symptoms. The most common symptoms experienced by all clients were pain (62%), fever (59%), lethargy and weight loss (each experienced by 56% of clients) (Table 4.3). The next most common were cough (48%), diarrhoea and anaemia (each experienced by 47% of clients) and dyspnoea and anorexia and/or reduced oral intake (each experienced by 44% of clients). Other common client symptoms were vomiting, sweats (each experienced by 37% of clients), nausea (33%), cognitive deficit (32%), headache (30%), and feeling weak and/or generally unwell (26%). These signs and symptoms were also among the most common of the 1,072 incidents of all referrals and the 322 incidents of initial referrals. When all clients and all referrals are compared, the variance of the most common signs and symptoms is due to their recurrence or persistence in clients on

subsequent referrals. The most common representing signs and symptoms were pain (39 representations), fever (28 representations), diarrhoea (27 representations), cough (21 representations) and dyspnoea (20 representations). The most common signs and symptoms amongst initial referrals in order of incidence were pain, fever, weight loss, lethargy, diarrhoea, anaemia, cough, anorexia, sweats and nausea.

Table 4.3 The Signs and Symptoms of Clients

Signs and Symptoms	All Clients (n=73)	All Referrals (n=171)	Representin g Signs and Symptoms Amongst All Referrals	Initial Referrals (n=49)
	Frequency (%)	Frequency (%)	Frequency	Frequency (%)
Pain	45 (62)	84 (49)	39	24 (49)
Fever	43 (59)	71 (42)	28	24 (49)
Weight Loss	41 (56)	58 (34)	17	21 (43)
Lethargy	41 (56)	54 (32)	13	21 (43)
Cough	35 (48)	56 (33)	21	17 (35)
Diarrhoea	34 (47)	61 (36)	27	18 (37)
Anaemia	34 (47)	50 (29)	16	18 (37)
Dyspnoea	32 (44)	52 (30)	20	10 (20)
Anorexia	32 (44)	48 (28)	16	13 (27)
Vomiting	27 (37)	39 (23)	12	9 (18)
Sweats	27 (37)	37 (22)	10	13 (27)
Nausea	24 (33)	35 (20)	11	12 (24)
Cognitive Deficit	23 (32)	36 (21)	13	9 (18)
Headache	22 (30)	29 (17)	7	7 (14)
Weak/Unwell	19 (26)	24 (14)	5	6 (12)
Other	305 incidents	338 incidents	33 incidents	100 incidents
Total	784 incidents	1,072 incidents	288 incidents	322 incidents
Nil Known	0 clients	0 referrals	-	0 clients
Not Stated	0 clients	3 referrals	-	0 clients

Note. Total signs and symptoms amongst all clients and referrals = 86.

4.3.2.1 Pain

When all clients are considered (n=73), there was a total of 107 incidents of conditions causing pain, with no known or documented incident for 38% (Table 4.4). When all referrals are considered (n=171), there was a total of

129 incidents of conditions causing pain and no known or documented incident for 51%. The most common condition causing pain amongst all clients and all referrals was headache, followed by CMV infection excluding retinitis, and diarrhoea. Other more common conditions causing pain included chest infection, odynophagia and hepatomegaly and/or splenomegaly. Apart from headache (7 representations), a similar pattern can be seen when the results are compared on the basis of numbers of clients and numbers of referrals, indicating the incidence of recurrence was not high amongst most of these conditions.

Table 4.4 Conditions Causing Clients Pain

Conditions	All Clients (n=73)	All Referrals (n=171)	Representing Conditions Amongst All Referrals
	Frequency (%)	Frequency (%)	Frequency
Headache	22 (30)	29 (17)	7
CMV infection	6 (8)	8 (5)	2
Diarrhoea	5 (7)	6 (4)	1
Chest infection	4 (5)	4 (2)	0
Odynophagia	4 (5)	4 (2)	0
Hepato/splenomegaly	4 (5)	4 (2)	0
Cholecystitis	3 (4)	4 (2)	1
Arthritis/Arthropathy	3 (4)	4 (2)	1
Peripheral Neuropathy	3 (4)	3 (2)	0
MAC	3 (4)	3 (2)	0
Cryptococcosis	3 (4)	3 (2)	0
Muscle pain	3 (4)	3 (2)	0
Other	44 incidents	54 incidents	10 incidents
Total	107 incidents	129 incidents	22 incidents
Nil Known/Not Stated	28 (38) clients	98 (51) referrals	-

Note. CMV infection = cytomegalovirus infection excluding retinitis; MAC = mycobacterium avium complex; Cryptococcosis = extrapulmonary. Other includes cholangitis, oral and/or dental disease, pneumothorax, fall and/or injury, oesophageal candida, cerebral toxoplasmosis, lymphoma and constipation.

There was a total of 95 incidents of documented site of pain experienced amongst all clients (n=73) and 130 incidents amongst all referrals (n=171)

(Table 4.5). There was nil known or nil stated site or type of pain for 62% of clients and 40% of referrals. The most commonly stated site of pain for all clients and referrals was the abdomen. Abdominal pain included that described as occurring in the abdominal, lower abdominal, epigastric and right upper quadrant regions. The other most commonly stated site of pain experienced by the clients was headache followed by pleuritic chest pain and non-cardiac/non-pleuritic chest pain. Other more commonly stated sites of pain amongst clients and referrals were joints, back, rectum and feet.

Table 4.5 Sites of Pain Amongst Clients

Conditions	All Clients (n=73)	All Referrals (n=171)	Representin g Conditions Amongst All Referrals
	Frequency (%)	Frequency (%)	Frequency
Abdomen	28 (38)	42 (25)	14
Headache	21 (29)	29 (17)	8
Pleuritic	8 (11)	9 (5)	1
Chest	7 (10)	7 (4)	0
Joint(s)	4 (5)	5 (3)	1
Rectum	3 (4)	4 (2)	1
Feet	3 (4)	3 (2)	0
Back	2 (3)	5 (3)	3
Other	19 incidents	26 incidents	7
Total	95 incidents	130 incidents	35 incidents
Nil Known/Not Stated	45 (62) clients	69 (40) referrals	-

Note. Chest pain = non-cardiac/non-pleuritic chest pain.

4.3.3 Clients' New Diagnoses and/or Reasons for Admission to the HIV/AIDS Unit

The new diagnoses and/or reasons for admission were identified to give an indication of the types of conditions that existed in clients during their admission to the HIV/AIDS Unit. Results are presented on the basis of all

clients, all referrals and initial referrals. The conditions are also presented on the basis of HIV Category and symptoms. In addition, the most common representing new diagnoses and/or reasons for admission are identified. The symptoms in this section represent the referrals for which the cause was undiagnosed or unclear on the CNRFs.

There were 511 new diagnoses or reasons for admission amongst all referrals (n=171) and 176 amongst initial referrals (n=49) (Table 4.6). The majority was non-HIV Category B or C conditions. When all referrals are considered (n=171), there was a total of 511 incidents comprised mainly of Non-HIV Category B or C conditions (52%) and HIV Category C conditions (24%). The initial referrals (n=49), comprised mainly non-HIV Category B or C conditions (59%) and HIV Category C conditions (25%).

Table 4.6 Total Incidences of New Diagnoses or Reasons for Admission to the HIV/AIDS Unit

	HIV Category C Condition s	HIV Category B Condition s	Non-HIV Category B or C Condition s	Symptom s	Total Condition s
All Referrals	123	46	266	76	511
Initial Referrals	44	15	103	14	176

Note. All clients (n=73): 423 incidences of total conditions including 64 symptoms. All referrals (n=171). Initial referrals (n=49). Total Conditions: Nil Known and Not Stated = 0 for all clients, all referrals and initial referrals.

When all clients are considered (n=73), there was a total of 423 incidents of conditions identified as a new diagnoses or reasons for admission to the HIV/AIDS Unit. When all clients are considered (n=73), the most common conditions were oral candida (32%), MAC (27%) and anaemia (26%) (Table 4.7). Other common conditions were fall or injury (18%); drug

allergy or intolerance; insertion, removal or review of a LTVAD (each 16%); CMV infection excluding retinitis; skin rash (each 15%); and depression (14%). These conditions were also among those most commonly identified when all referrals and initial referrals are considered.

When the incidence of all clients and all referrals are compared, the variance of the most common conditions is due to their recurrence in clients on subsequent referrals. The most common representing conditions were anaemia (9 representations), KS (6 representations), oral candida, MAC and chest infection (each having 4 representations). The most common conditions amongst initial referrals in order of incidence were oral candida, MAC, insertion, removal or review of LTVAD, depression, CMV infection excluding retinitis, drug allergy or intolerance, skin rash, chest infection and PCP.

Table 4.7 The Reasons for Admission or New Diagnoses of Clients on Admission to the HIV/AIDS Unit

Category	Conditions	All Clients (n=73) Frequency (%)	All Referrals (n=171) Frequency (%)	Representin g New Dx/RFA Frequency	Initial Referrals (n=49) Frequency (%)
B	Oral Candida	23 (32)	27 (16)	4	11 (22)
C	MAC	20 (27)	24 (14)	4	9 (18)
S/S	Anaemia	19 (26)	28 (16)	9	5 (10)
Non B or C	Fall/Injury	13 (18)	13 (8)	0	4 (8)
Non B or C	Drug Intolerance	12 (16)	13 (8)	1	6 (12)
Non B or C	LTVAD	12 (16)	15 (9)	3	8 (16)
C	CMV Infection	11 (15)	12 (7)	1	7 (14)
Non B or C	Skin Rash	11 (15)	13 (8)	2	6 (12)
Non B or C	Depression	10 (14)	11 (6)	1	8 (16)
Non B or C	IV therapy	9 (12)	9 (5)	0	2 (4)
Non B or C	Respite	9 (12)	10 (6)	1	3 (6)
Non B or C	Chest Infection	9 (12)	13 (8)	4	6 (12)
C	Presumptive PCP	8 (11)	9 (5)	1	3 (6)
S/S	Diarrhoea	8 (11)	9 (5)	1	1 (2)
C	Cryptosporidia	7 (10)	10 (6)	3	0
C	KS	6 (8)	12 (7)	6	1 (2)
C	PCP	6 (8)	6 (4)	0	6 (12)
Non B or C	IV Line Infection	6 (8)	7 (4)	1	3 (6)
B	Microsporidia	6 (8)	7 (4)	1	1 (2)
Non B or C	Herpes Simplex	6 (8)	8 (5)	2	2 (4)
Non B or C	Ulcer(s)	6 (8)	6 (4)	0	1 (2)
Non B or C	Palliation	6 (8)	6 (4)	0	1 (2)
C	HIV				
	Encephalopathy	5 (7)	6 (4)	1	2 (4)
C	Oesophageal				
	Candida	5 (7)	6 (4)	1	1 (2)
C	CMV Retinitis	5 (7)	5 (3)	0	3 (6)
B	Peripheral				
	Neuropathy	5 (7)	6 (4)	1	1 (2)
S/S	Seizure	4 (5)	4 (2)	0	0
S/S	Acopia	4 (5)	5 (3)	1	1 (2)
	Other	182 incidents	211 incidents	57 incidents	74 incidents
	Total	423 incidents	511 incidents	88 incidents	176 incidents
	Nil Known	0 Clients	0 Clients	-	0 Clients
	Not Stated	0 Clients	0 Clients	-	0 Clients

Note. Category = HIV Category B, C or Non B or C condition or sign or symptom. MAC = Mycobacterium avium complex; LTVAD = long term venous access device; CMV = Cytomegalovirus; CMV Infection = excludes CMV retinitis; IV = IV; PCP = Pneumocystis Carinii Pneumonia; KS = Kaposi's Sarcoma; ITP = idiopathic thrombocytopenia purpura; OHL = oral hairy leukoplakia; Ulcer(s) = of undiagnosed or unstated cause.

4.4. Associations of Selected Clinical Variables

Some of the most commonly occurring clinical variables were investigated to measure the strength of the relationships between them. Variables which were cross tabulated for concordance included commonly identified:

- a) new diagnoses/reasons for admission and symptoms;
- b) new diagnoses/reasons for admission and pain sites;
- c) symptoms causing pain and pain sites;
- d) diagnoses causing pain and symptoms causing pain;
- e) diagnoses causing pain and pain sites; and
- f) selected symptom and psychoemotional status variables common to HIV encephalopathy.

No concordance (as indicated by the kappa value) was found between any of the variables that were cross tabulated. They are now presented.

4.4.1 New Diagnoses/Reasons for Admission and Signs and Symptoms

Of all referrals (n=171), the most commonly occurring conditions for new diagnoses/reasons for admission were cross tabulated with the most commonly occurring signs and symptoms. Results are displayed in Table 4.8.

When all referrals are considered, those which documented anaemia as the new diagnosis or reason for admission (16%), it was indicated the client also experienced the symptoms of anaemia (13%), cough (9%) and fever (8%). When only the 16% of all client referrals stating anaemia was a new diagnosis/reason for admission are considered (n=28) the most common coexisting signs and symptoms were anaemia (79%), cough (57%) and fever (50%).

Table 4.8 Coexistence of Commonly Identified New Diagnoses/ Reasons for Admission and Commonly Identified Symptoms

New Dx/RFA		Symptoms							
		Pain	Fever	Diarrhoea	Weight loss	Cough	Lethargy	Anaemia	Anorexia
Total Referrals (n=171)		84 (49%)	71 (42%)	61 (36%)	58 (34%)	56 (33%)	54 (32%)	50 (29%)	48 (28%)
Anaemia	28 (16%)	12 (7%)	14 (8%)	12 (7%)	8 (5%)	16 (9%)	3 (2%)	22 (13%)	na
Oral Candida	27 (16%)	13 (8%)	17 (10%)	12 (7%)	12 (7%)	12 (7%)	11 (6%)	10 (6%)	na
MAC	24 (14%)	12 (7%)	14 (8%)	10 (6%)	11 (6%)	7 (4%)	13 (8%)	11 (6%)	na
LTVAD	15 (9%)	10 (6%)	10 (6%)	9 (5%)	4 (2%)	6 (4%)	5 (3%)	5 (3%)	na
Fall/Injury	13 (8%)	8 (5%)	8 (5%)	5 (3%)	na	6 (4%)	6 (4%)	7 (4%)	3 (2%)
Chest Infection	13 (8%)	10 (6%)	10 (6%)	2 (1%)	na	7 (4%)	4 (2%)	3 (2%)	1
Drug Intolerance	13 (8%)	3 (2%)	6 (4%)	8 (5%)	na	3 (2%)	4 (2%)	5 (3%)	2 (1%)
Skin Rash	13 (8%)	6 (4%)	7 (4%)	8 (5%)	na	5 (3%)	5 (3%)	1	5 (3%)
CMV	12 (7%)	5 (3%)	7 (4%)	6 (4%)	na	4 (2%)	7 (4%)	5 (3%)	4 (2%)
Depression	11 (6%)	1	6 (4%)	3 (2%)	na	1	3 (2%)	4 (2%)	3 (2%)
Cryptosporidia	10 (6%)	6 (4%)	3 (2%)	7 (4%)	na	3 (2%)	2 (1%)	1	4 (2%)
Respites	10 (6%)	5 (3%)	3 (2%)	4 (2%)	na	2 (1%)	3 (2%)	1	3 (2%)
Presumptive PCP	9 (5%)	2 (1%)	5 (3%)	2 (1%)	na	5 (3%)	3 (2%)	2 (1%)	1
IV Therapy	9 (5%)	5 (3%)	3 (2%)	2 (1%)	na	3 (2%)	1	3 (2%)	1
PCP	6 (4%)	3 (2%)	2 (1%)	3 (2%)	na	4 (2%)	1	2 (1%)	3 (2%)

Note. New Dx/RFA = new diagnoses or reasons for admission, MAC = Mycobacterium avium complex, LTVAD = long term venous access device,

PCP = presumptive carinii pneumonia, IV = intravenous, na = not analysed.

When all referrals are considered, those which documented oral candida as the new diagnosis or reason for admission (16%), it was indicated the client also experienced fever (10%) and pain. When only the 16% of all referrals with oral candida as a new diagnosis/reason for admission are considered (n= 27), the most common coexisting sign or symptom was fever (63%).

When all referrals are considered, those which documented MAC as the new diagnosis or reason for admission (14%), it was indicated the client also experienced fever, lethargy (each 8%) and pain (7%). When only the 14% of client referrals with MAC as a new diagnosis or reason for admission are considered (n= 24) the most common coexisting signs and symptoms were fever (58%); lethargy (54%) and pain (50%).

When all referrals are considered, those which documented LTVAD as the new diagnosis or reason for admission (9%), the most common coexisting signs and symptoms were fever (each 6%) and diarrhoea (5%). When only the 9% of all client referrals with LTVAD as a new diagnosis/reason for admission are considered (n= 15) the most common signs and symptoms were pain (67%); fever (67%) and diarrhoea (60%).

When only the client referrals with fall and/or injury as a new diagnosis or reason for admission are considered (n=13), the most common signs and symptoms coexisting in the clients were pain, fever (each 62%) and anaemia (54%). When only the client referrals with chest infection as a new diagnosis or reason for admission are considered (n=13), the most common signs and symptoms coexisting in the clients were pain, fever (each 77%) and cough (54%). When only the client referrals with drug allergy and/or intolerance as a new diagnosis or reason for admission are considered (n=13), the most common sign or symptom coexisting in the clients was diarrhoea (62%). When only the client referrals with skin rash as a new diagnosis or reason for admission are considered (n=13), the most

common signs and symptoms coexisting in the clients were diarrhoea (62%) and fever (54%).

When only the client referrals with CMV disease excluding retinitis as a new diagnosis or reason for admission are considered (n=12), the most common signs and symptoms coexisting in the clients were fever, lethargy (each 58%), and diarrhoea (50%). When only the client referrals with depression as a new diagnosis or reason for admission are considered (n=11), the most common sign or symptom coexisting in clients was fever (55%). When only the client referrals with cryptosporidia as a new diagnosis or reason for admission are considered (n=10), the most common signs and symptoms coexisting in the clients were diarrhoea (70%) and pain (60%). When only the client referrals with respite as a new diagnosis or reason for admission are considered (n=10), the most common sign or symptom coexisting in the clients was pain (50%).

When only the client referrals with presumptive PCP as a new diagnosis or reason for admission are considered (n=9), the most common signs and symptoms coexisting in the clients were fever and cough (each 56%). When only the client referrals with IV therapy as a new diagnosis/reason for admission are considered (n=9), the most common sign or symptom experienced by the clients was pain (56%). When only the client referrals with PCP as a new diagnosis or reason for admission are considered (n=6), the most common signs and symptoms coexisting in the clients were cough (67%), pain, diarrhoea and anorexia (each 50%).

4.4.2 Pain Sites and New Diagnoses/Reasons for Admission, Pain Symptoms and Pain Diagnoses

Of all client referrals (n=171), the most commonly found pain sites of abdomen, pleuritic, non-cardiac/non-pleuritic chest and joint(s) were cross

tabulated with the most commonly occurring variables for new diagnoses or reasons for admission, pain symptoms and pain diagnoses. Results are displayed in Table 4.9.

When only the total referrals for the clients' new diagnoses or reasons for admission are considered, those most commonly coexisting with abdominal pain were diarrhoea (56% of 9 referrals) and CMV disease excluding retinitis (42% of 12 referrals). When only the total referrals for the symptoms causing pain are considered, those most commonly occurring with abdominal pain were diarrhoea (100% of 6 referrals) and odynophagia (50% of 4 referrals). When only the total client referrals for the diagnoses causing pain are considered, those which most commonly also stated the client was experiencing abdominal pain, were cholecystitis (100% of 4 referrals), CMV infection excluding retinitis (88% of 8 referrals) and MAC (67% of 3 referrals). Seventy five percent of the 4 referrals stating the client had a diagnosis causing pain of arthritis stated the pain site to be joint(s). Fifty percent of the 4 referrals that stated the client had the diagnosis causing pain of extrapulmonary cryptococcus stated the client had non-cardiac/non-pleuritic chest pain.

Table 4.9 Coexistence of Commonly Identified Pain Sites with Commonly Identified New Diagnoses or Reasons for Admission, Pain Symptoms and Pain Diagnoses

New Diagnoses		Pain Sites			
		Abdominal	Pleuritic	Chest	Joint
	Total Referrals (n=171)	42 (25%)	9 (5%)	7 (4%)	5 (3%)
Oral Candida	27 (16%)	6 (4%)	0	1	1
Venous Access Device	15 (9%)	4 (2%)	0	2	0
Chest Infection	13 (8%)	5 (3%)	3 (2%)	1	0
Cytomegalovirus	12 (7%)	5 (3%)	0	0	0
Cryptosporidia	10 (6%)	3 (2%)	0	0	1
Diarrhoea	9 (5%)	5 (3%)	1	0	0
Pain Symptoms					
Headache	29 (17%)	9 (5%)	0	0	0
Diarrhoea	6 (4%)	6 (4%)	1	0	0
Odynophagia	4 (2%)	2	1	0	1
Pain Diagnoses					
Cytomegalovirus	8 (5%)	7 (4%)	0	0	
Arthritis	4 (2%)	0	0	0	3 (2%)
Cholecystitis	4 (2%)	4 (2%)	0	0	
Cryptococcus	3 (2%)	0	0	2	
Mycobacterium Avium	3 (2%)	2	0	0	
Kaposi's Sarcoma	3 (2%)	1	0	0	

4.4.3 Pain Diagnoses and Pain Symptoms

From all referrals (n=171), the most commonly found pain symptoms were cross tabulated with the most commonly occurring variables for pain diagnosis. Results are displayed in Table 4.10. When only the total referrals for the diagnoses causing pain are considered, the highest percentage also occurring in referrals stating the client was experiencing the symptom causing pain of headache was MAC (67% of 3 referrals).

4.4.4 Selected Diagnosis, Symptom and Psychoemotional Status Variables Common to HIV Encephalopathy

The variables which were cross tabulated with the clients' past diagnosis and the new diagnosis or reason for admission of HIV encephalopathy and the symptom of cognitive deficit were the psychoemotional status variables of depressed mood, anxiety and withdrawn. Results are displayed in Table 4.11. From all referrals (n=171), documenting the client had a previous diagnosis of confirmed or presumptive HIV encephalopathy (5%) there were no referrals which also stated the client had a cognitive deficit or was depressed, anxious or withdrawn. From the 4% of all client referrals documenting that the client had a new diagnosis or reason for admission of HIV encephalopathy, only 1% or less stated that the client also had a depressed mood, or was anxious or withdrawn. From the 21% of all client referrals documenting the client experienced the symptom of a cognitive deficit, only 4% were identified as also having a depressed mood, and 2% or less were also documented to be withdrawn or feeling anxious.

Table 4.10 Coexistence of Commonly Identified Pain Symptoms and Commonly Identified Pain Diagnoses

Pain Diagnoses		Pain Symptoms			
		Headache	Diarrhoea	Odynophagia	Hepato/Spleno - megaly
	Total Referrals (n=171)	29 (17%)	6 (4%)	4 (2%)	4 (2%)
Cytomegalovirus	8 (5%)	0	0	1	0
Cholecystitis	4 (2%)	1	0	0	0
Arthritis	4 (2%)	0	0	1	0
Chest Infection	4 (2%)	0	1	0	0
Cryptococcus	4 (2%)	1	0	0	0
Peripheral Neuropathy	3 (2%)	0	0	0	0
Mycobacterium Avium	3 (2%)	2	0	0	0

Table 4.11 Coexistence of Conditions Common to HIV Encephalopathy

Psychoemotional Status		Conditions		
		Past History HIV Encephalopathy	New Diagnosis/Reason for Admission HIV Encephalopathy	Symptom Cognitive Deficit
	Total Referrals (n=171)	9 (5%)	6 (4%)	36 (21%)
Depressed Mood	30 (18%)	0	1	6 (4%)
Anxious	26 (15%)	0	0	2
Withdrawn	10 (6%)	0	2	3 (2%)

4.4.5 Variables Identified to Coexist Most Frequently

Variables that occurred in at least 5% of all referrals (n=171) and were identified to coexist most frequently are presented in Table 4.12. The symptoms of fever, pain and diarrhoea were identified most frequently.

Table 4.12 Variables of Clients Indicated by the Study to Coexist Most Frequently

Groups Examined	Variables with Possible Associations
New dx/RFA with signs and symptoms	Anaemia with cough, fever, <i>pain or diarrhoea</i> ; Oral candida with fever, <i>pain, diarrhoea, weight loss, cough or lethargy</i> ; MAC with fever, lethargy, pain, <i>anaemia, weight loss or diarrhoea</i> ; LTVAD with pain, fever or diarrhoea; fall or injury with pain, fever or anaemia; chest infection with pain, fever or cough; drug allergy or intolerance with diarrhoea <i>or fever</i> ; skin rash with diarrhoea, fever <i>or pain</i> ; CMV infection with fever, lethargy or diarrhoea; depression with fever; cryptosporidia with diarrhoea or pain; respite admission with pain; PCP with fever or cough; and IV therapy with pain.
New dx/RFA with pain site	Diarrhoea with abdominal pain; CMV infection with <i>abdominal pain</i> .
Pain symptom with pain site	Diarrhoea with abdominal pain
Pain diagnosis with pain site	CMV infection with abdominal pain;

Note. All variables occurred in at least 5% of all referrals (n=171) and coexisted in at least 50% of cases except for those in italics which coexisted in 41-49% of cases (Refer to Tables 4.8-4.11); New dx/RFA = new diagnosis or reason for admission; MAC = mycobacterium avium complex; LTVAD = long term venous access device; CMV infection = cytomegalovirus infection excluding retinitis; PCP = pneumocystis carinii pneumonia.

4.5 The Ongoing Issues and Continuing Treatments on Referral

Ongoing issues and continuing treatments refer to areas that were either unresolved or required continuing intervention at the time the client was referred to the community nurse. In this section, the incidence of the ongoing issues and ongoing treatments of clients is presented on the basis of all clients, all referrals, representing issues and initial referrals.

When all clients are considered (n=73), there was a total of 89 incidents concerning the clients' ongoing issues on referral to community nursing services. The most common ongoing issues on the basis of all clients were palliation (12%), fever (10%) and diarrhoea (8% of clients) (Figure 4.18). Other more common issues included cognitive deficit, cough, IV therapy, restricted self care, diabetes and vomiting.

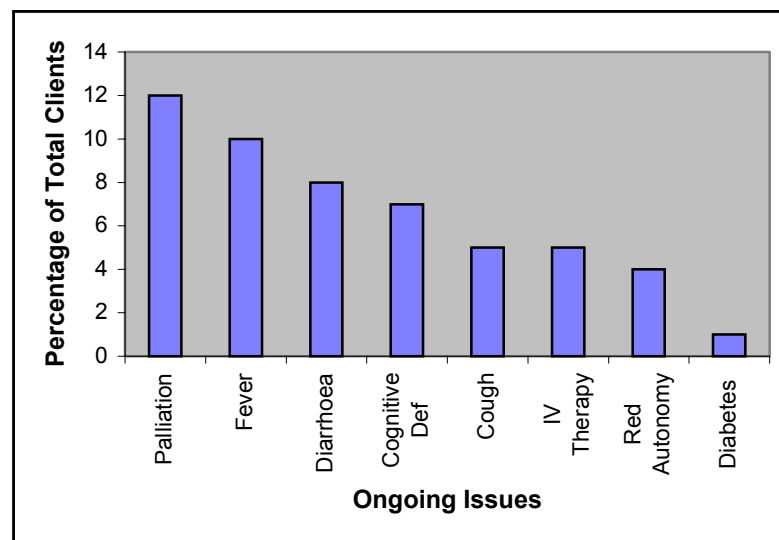


Figure 4.18 Ongoing Issues on Referral of all Clients (n = 73). Other = 50, Total Incidents = 89. Cognitive Def = cognitive deficit, IV Therapy = IV therapy; Red. Autonomy = reduced autonomy.

When all referrals are considered (n=171), there was a total of 103 incidents of ongoing issues for the clients and no specific ongoing issue stated for 42%. The most common issues were similar to those identified per client, however IV therapy was slightly less common (Figure 4.19). The most common representing ongoing issues were diabetes (3 representations), reduced autonomy, cough and diarrhoea (each having one representation). When only initial referrals are considered (n=49), there was a total of 28 documented incidences of ongoing issues. The most common were palliation and fever, with each occurring in 6% of referrals. Others included cough, diarrhoea, restricted self care and IV therapy. When compared to all referrals, diarrhoea was less common, and there was no incidence of cognitive deficit or diabetes.

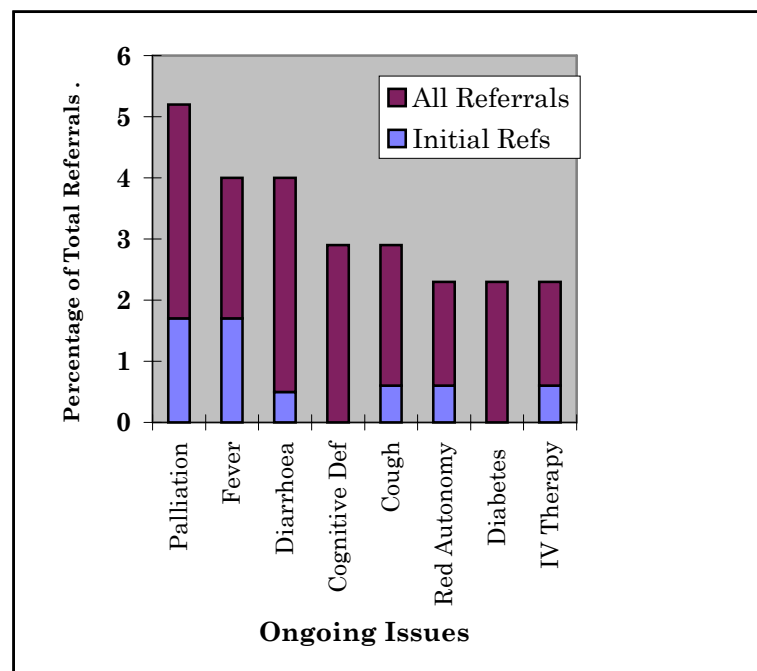


Figure 4.19 Ongoing Issues on Referral of All Referrals and Initial Referrals All Referrals n = 171, Other = 58 Incidents, Total = 103 incidents, Not Stated = 42% of referrals. Initial Referrals n = 49, Other = 18 incidents, Total Incidents = 28. Cognitive Def = cognitive deficit, Red. Autonomy = reduced autonomy and IV Therapy = IV therapy.

When all clients are considered (n=73), there were 150 incidents of ongoing treatments on referral to community nursing services. Oral medication was an ongoing treatment of 100% of clients. The next most common treatments were inhaled medications, topical medications, IV medications, nasogastric or enteral feeds and subcutaneous medications (Figure 4.20).

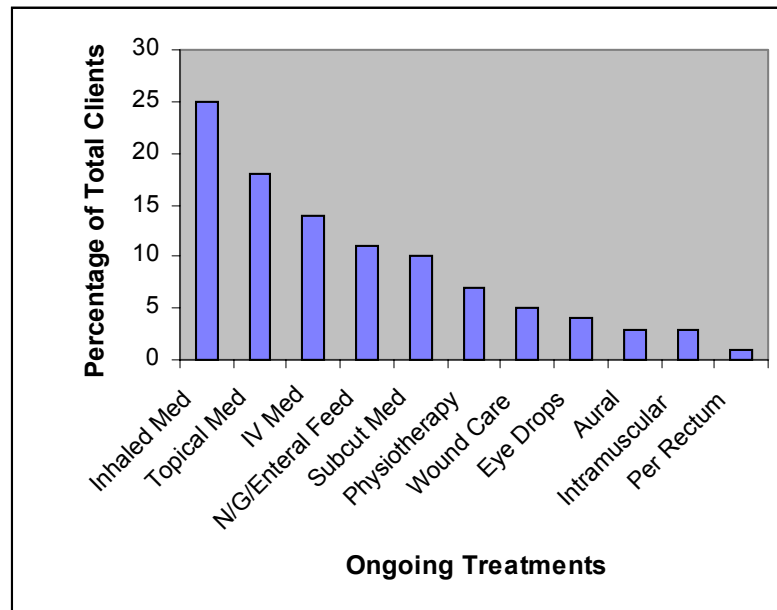


Figure 4.20 Ongoing Treatments Of All Clients on Referral (n=73).

Total Incidents = 150, Oral medication = 100% of all clients, Other = 4. Med = medication, IV = Intravenous, N/G/Enteral = nasogastric or enteral, subcut = subcutaneous.

From all referrals (n=171), clients had a total of 279 continuing treatments on referral to community nursing services of which 78 were among initial referrals. The most commonly occurring treatments were similar to those identified on the basis of clients with oral medication prescribed to clients in 100% of all referrals. On comparison of initial referrals to all referrals, IV medication was more common amongst initial referrals (Figure 4.21).

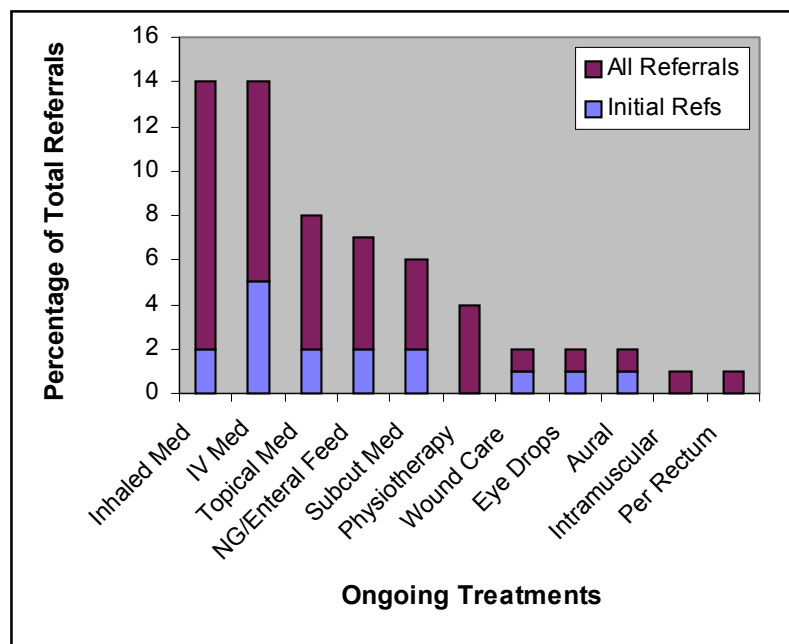


Figure 4.21 Ongoing Treatments on Referral Amongst All Referrals

and Initial Referrals All Referrals: (n=171) Total Incidents = 279, Oral medication = 100% of all clients, Other = 4. Med = medication, IV = IV, N/G/Enteral = nasogastric or enteral, subcut = subcutaneous. Initial Refs = Initial Referrals: (n=49), Total Incidents = 78, Oral medication = 100% of all clients, Other = 2.

From the 24 referrals of 10 clients who had IV therapy as an ongoing treatment on referral to community nursing services, the medications in order of incidence were ganciclovir, antibiotics, foscarnet and amphotericin. There were 10 incidents of IV therapy amongst all clients (Figure 4.22), 24 amongst all referrals and 8 amongst initial referrals (Figure 4.23). The only representing medication was ganciclovir (13 representations). Some clients were prescribed more than one IV medication on each referral.

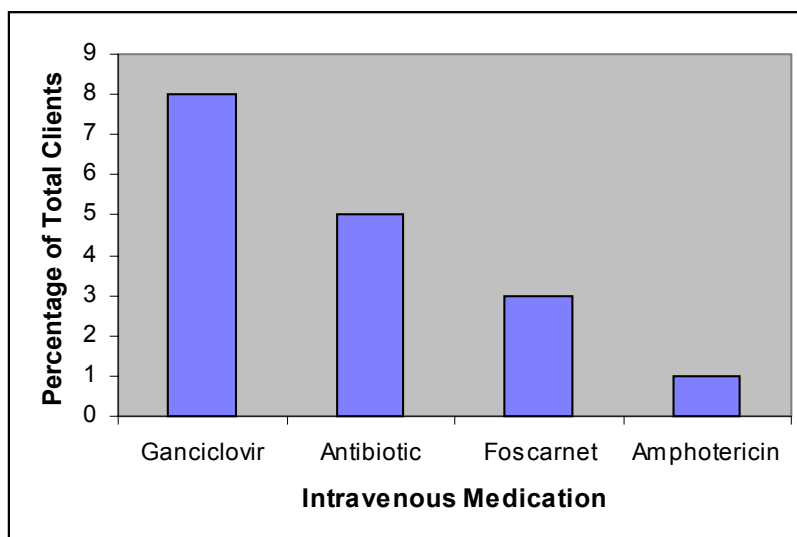


Figure 4.22 Ongoing IV Therapies on Referral Amongst All Clients
(n=73). Total Incidents = 10.

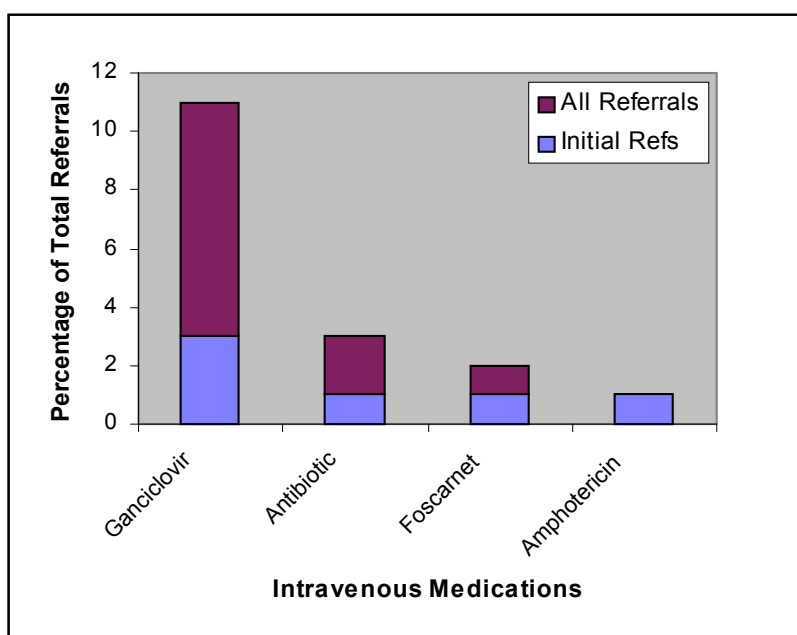


Figure 4.23 Ongoing IV Therapies on Referral Amongst All Referrals and Initial Referrals All Referrals: (n=171), Total Incidents = 8; Initial Refs = Initial Referrals (n=49), Total Incidents = 24.

4.6 The Physical Abilities of Clients on Referral

The clients' abilities to mobilise, attend to their personal care and their home duties are presented in this section. The incidence is presented on the basis of all clients on Referral 1, all referrals and initial referrals. The data was collected under the headings of with aid, immobile (for mobility only), independent, with assistance, as able or tolerated (indicating limitations), with supervision, not stated and other. As each referral may have indicated one or more of these headings for each of the client's abilities, the incidence may be greater than the total clients or referrals.

When Referral 1 of all clients are considered, there were 82 descriptions of the clients' mobility status. The majority of clients were independent in their mobility (85%) and 14% were ambulant 'as tolerated' (Figure 4.24). Walking aids were required for 7% of clients of which one was a wheelchair. One client required assistance, and one client was immobile.

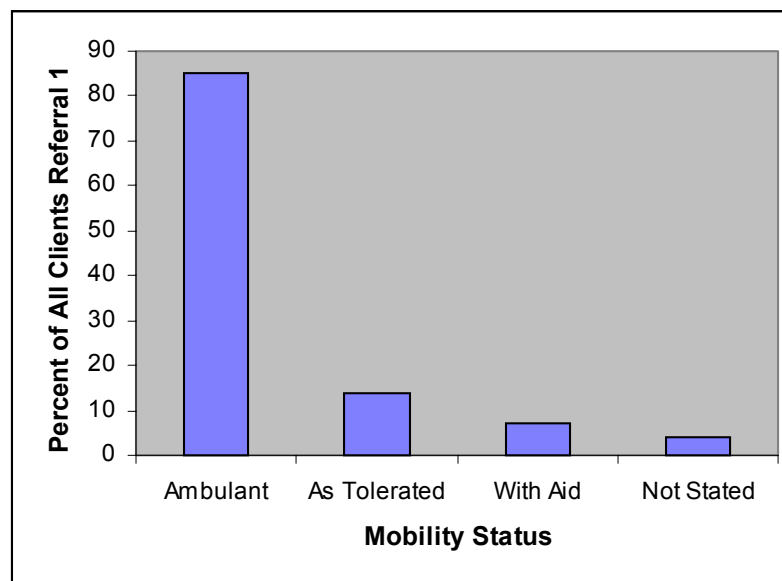


Figure 4.24 The Clients' Mobility Status on Referral 1 of All Clients (n=73). Other = 2 incidents, Total incidents = 82.

Of all client referrals (n=171), 74% of clients were ambulant; 9% ambulant with an aid; 6% ambulant as tolerated; and 5% did not document the mobility status. On comparison with initial referrals (n=49), the use of walking aids increased on subsequent referrals (Figure 4.25).

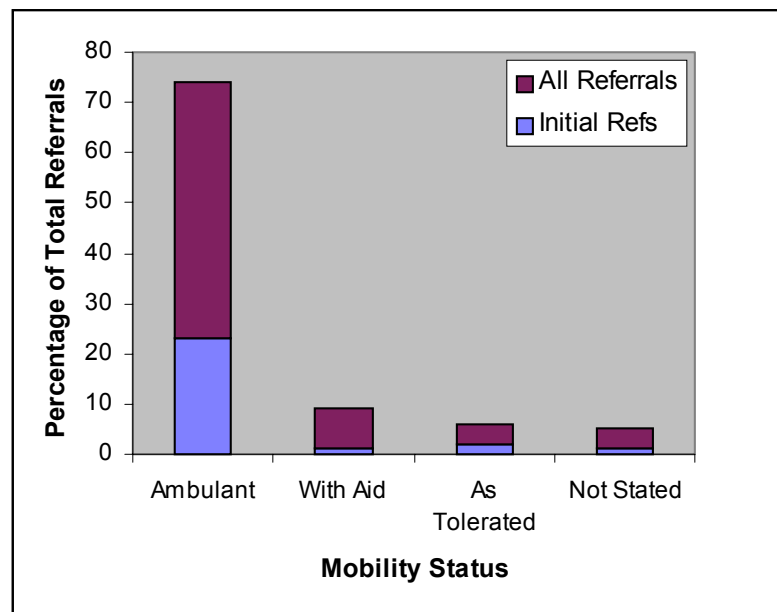


Figure 4.25 The Clients' Mobility Status Amongst All Referrals and Initial Referral All Referrals (n=171). Other = 11 incidents. Initial refs = Initial Referrals (n=49). Other = 2 incidents.

On Referral 1 (n=73), there were 76 descriptions of the clients' personal care status. The majority of clients were independent in their personal care status (53%). The next most common finding was 'as tolerated' and with assistance (each 12%) and 7% of clients required supervision (Figure 4.26). No indication of personal care status was given for 18% of clients. When all referrals (n=171) and initial referrals (n=49) are considered, the findings are similar to those identified on Referral 1 of all clients (Figure 4.27).

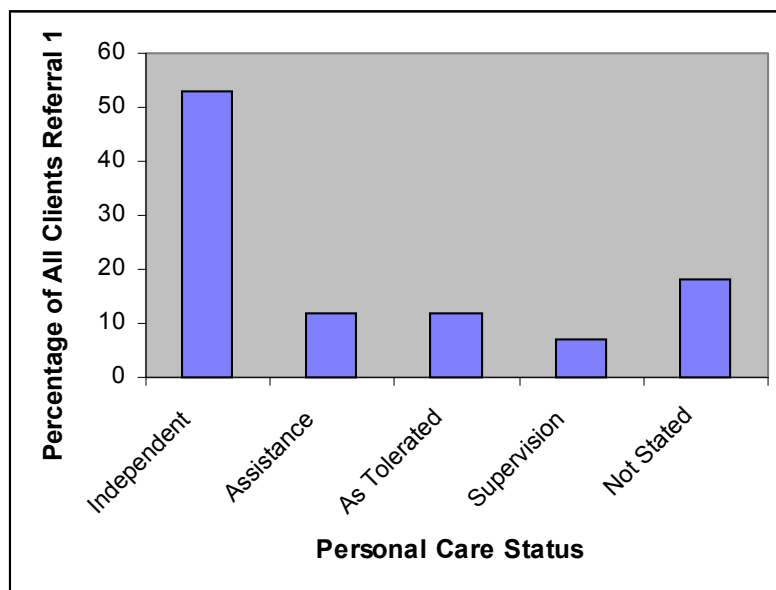


Figure 4.26 The Clients' Abilities to Attend to Their Personal Care on Referral 1 of All Clients (n=73). Total Incidents = 76, Other = 1.

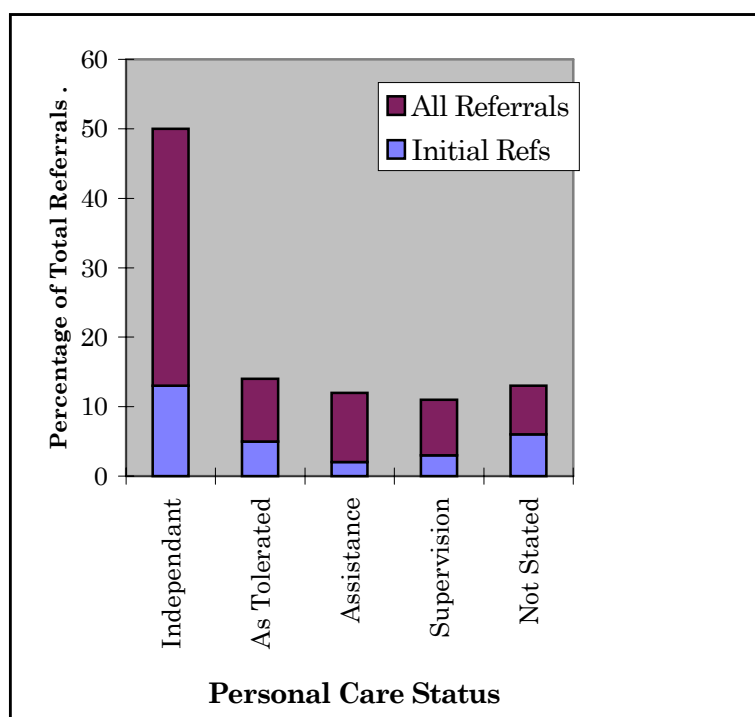


Figure 4.27 The Clients' Abilities to Attend to Their Personal Care Amongst All Referrals and Initial Referrals All Referrals n=171; Initial refs = Initial Referrals (n=49).

When Referral 1 of all clients are considered (n=73), there were 76 descriptions of the clients' abilities to perform household duties. Almost half of clients were independent in their personal care status (47%) (Figure 4.28). The next most common findings were 'with assistance' (22%), 'as tolerated' (14%) and 5% of clients required supervision. One client was documented as dependent with their household duties. No indication was given for 15% of clients. When all referrals (n=171) and initial referrals (n=49) are considered, the findings are similar to those identified on Referral 1 of all clients (Figure 4.29).

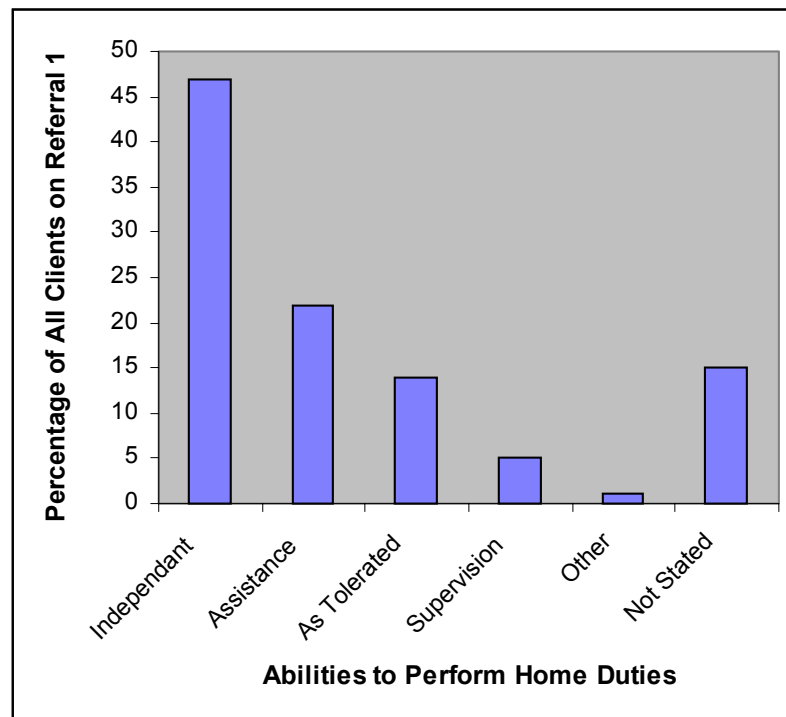


Figure 4.28 The Clients' Abilities to Perform Household Duties on Referral 1 of All Clients (n=73). Total Conditions = 76.

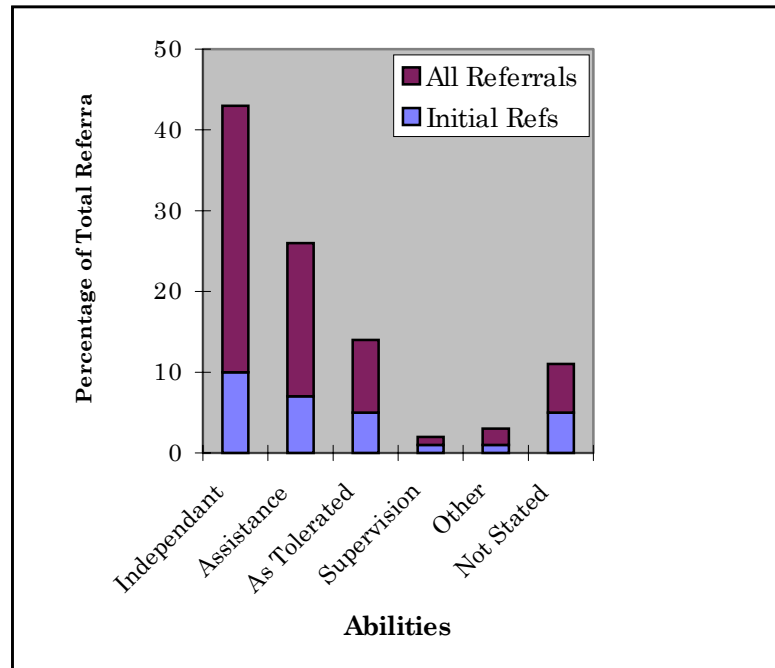


Figure 4.29 The Clients' Abilities to Perform Household Duties Amongst All Referrals and Initial Referrals All Referrals n=171. Initial Refs = Initial Referrals (n=49).

4.7 The Psychoemotional Status of Clients

The psychoemotional status of the clients referred to their recent or current psychological and/or emotional state at the time of referral to community nursing services. Identified variables are presented on the basis of all clients, all referrals, representations and initial referrals.

There were 143 incidents of 27 psychoemotional status variables amongst all clients (n=73). Those most commonly experienced were depressed mood, anxious, grieving, 'non-compliant' and withdrawn (Table 4.13). Other common variables were angry, worried, vague, fearful and unhappy. These were also among the most common of the 167 incidents of all referrals and the 57 incidents of initial referrals. The psychoemotional status was not stated for 34% of all clients, 46% of all referrals and 39%

of initial referrals. When all clients and all referrals are compared, the variance of incidence is due to recurrence in clients on subsequent referrals. Those most commonly representing were anxious, depressed mood and 'non-compliant'. The most common variables of initial referrals were depressed mood, withdrawn, anxious and angry.

Table 4.13 The Psychoemotional Status of Clients

Psychoemotional Status	All Clients (n=73)	All Referrals (n=171)	Representations	Initial Referrals (n=49)
	Frequency (%)	Frequency (%)	Frequency	Frequency (%)
Depressed	26 (36)	30 (18)	4	12 (24)
Anxious	21 (29)	26 (15)	5	6 (12)
Grieving	10 (14)	13 (8)	3	4 (8)
Non Compliant	9 (12)	13 (8)	4	4 (8)
Withdrawn	9 (12)	10 (6)	1	7 (14)
Angry	7 (10)	10 (6)	3	5 (10)
Worried	7 (10)	7 (4)	0	4 (8)
Vague	6 (8)	9 (5)	3	2 (4)
Fearful	6 (8)	6 (4)	0	2 (4)
Unhappy	6 (8)	6 (4)	0	2 (4)
Frustrated	5 (7)	5 (3)	0	1 (2%)
Restless	5 (7)	5 (3)	0	0
Other	26 incidents	27 incidents	1	9 incidents
Total	143 incidents	167 incidents	24 incidents	57 incidents
Nil Stated	24 (34%)	78 (46%)	—	19 (39%)

Note. Total psychoemotional variables identified = 27

4.7.1 Emergent Categories

In this section the findings from the qualitative analysis of the most commonly identified psychoemotional variables are presented. The most commonly occurring variables of despondent/depressed mood, distress/stress/anxiety, grief issues and ‘non-compliant/uncooperative’ were further explored using content analysis (Table 4.14). Eight broad categories, each with related specific categories emerged (Table 4.15), the most common being the physical effects of HIV/AIDS illness. The categories will now be presented further in relation to the psychoemotional variables they describe.

Table 4.14 Psychoemotional Variables Explored Using Content Analysis

Variables	Number of Incidents	Number of Referrals
Despondent/Depressed Mood	31	30 (18%)
Distress/Stress/Anxiety	27	26 (15%)
Grief Issues	18	13 (8%)
‘Non-compliant/ Uncooperative’	17	13 (8%)

Note. Total incidents of all documented psychoemotional variables: All Clients = 143, All Referrals = 167. Total Referrals: n=171.

Table 4.15 The Categories Emerging From Psychoemotional Status Variables

Broad Categories	Specific Categories/Associations
Physical Effects of HIV/AIDS Illness	Signs and Symptoms; Results of Clinical Investigations; and Reduced Ability
HIV/AIDS Conflict Issue(s) with Others	Family; Partner
Death	Personal Anticipatory Death; Death of Other
Personal Adjustment to HIV/AIDS Illness	Loss of Control; Life Change
Clinical Intervention	Nursing Care; Surgery; Investigative Procedures; Treatment
Hospitalisation	Associated with the client's admission, hospitalisation or discharge period
Home Environment	Associated with the client's home environment
Nil Further Explanation	This category is used when no additional information directly describing the examined psychoemotional status variable was documented

4.7.1.1 Despondent/Depressed Mood

The broad categories that related directly to the 31 incidents of despondent/depressed mood amongst all referrals were identified. They were: Physical Effects of HIV/AIDS Illness (five incidents or 16%); Personal Adjustment to HIV Illness (2 incidents); Death (one incident only); Clinical Intervention (one incident only); and Nil Further Explanation (22 incidents or 71%) (Figure 4.30).

Three of the five incidents described as being due to the physical effects of HIV/AIDS illness pertained to the specific category of client signs and symptoms which were further described as pain, hiccups and diarrhoea. One example of documented information was “episodes of diarrhoea cause client to feel depressed” (client code 71/Referral 2). The remaining two incidents related to the specific categories concerning the results of clinical investigations (reduced CD4 count) and reduced ability (mobility).

Of the two incidents of despondent/depressed mood of the clients represented in the broad category of personal adjustment to HIV illness, both pertained to the specific category of loss of control. One incident was further described as being the effects of setbacks in health. The other was documented as “reactive depression due to loss of control related to his illness” (client code 43/Referral 1).

The broad category of death was represented only once, referring to a client whose friend died. Clinical intervention was only represented once and pertained to the specific category of surgery. The documented data stated “client depressed and disappointed op. was cancelled” (client code 52/Referral 2). Of the clients whose incidence of depression was not further explained, one questioned the value of his treatment, one felt the quality of

his life was very much compromised, and one client's depression was described as "severe".

4.7.1.2 Distress/Stress/Anxiety

The broad categories that related directly to the 27 incidents of distress/stress/anxiety amongst all referrals were identified. They were: the Physical Effects of HIV/AIDS Illness (five incidents or 19%); HIV/AIDS Conflict Issues with Other(s), Personal Adjustment to HIV Illness, and Clinical Intervention (each four incidents or 15%); Hospitalisation (three incidents); Home Environment (only one incident); and Nil Further Explanation (six incidents or 22%) (Figure 4.31).

All of the five incidents of distress/stress/anxiety categorised as being due to the physical effects of HIV/AIDS were represented in the specific category of signs and symptoms. Four of the signs and symptoms experienced by the clients were dysphagia, persistent cough, shortness of breath and headache. An example of the documented data follows: "client became quite anxious when he had headache [date] and stated he 'wasn't ready to go yet'," (client code 71/Referral 2).

Three of the incidents of HIV/AIDS conflict issues with other(s) were represented by the specific category of family. One client's illness and hospitalisation caused conflict with his family and the other's was caused by the fact his parents were staying at his house. The remaining incident of conflict was represented by the specific category of partner. The documented data was as follows: "Disclosure of HIV status has caused stress to both client and partner" (client code 32/Referral 2). It was also documented the client's partner was seeking an HIV test.

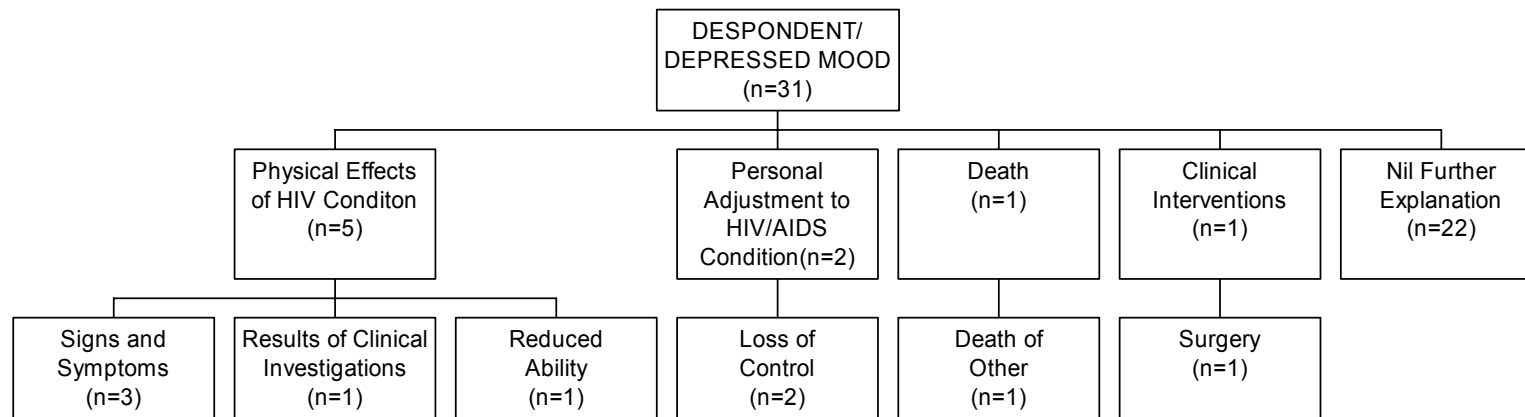


Figure 4.30 The Broad and Specific Categories of Despondent/Depressed Mood

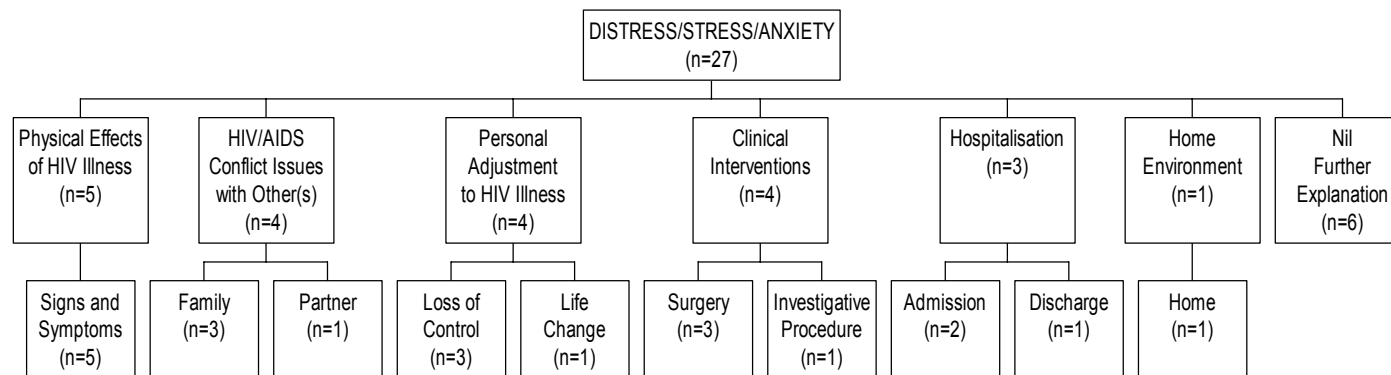


Figure 4.31 The Broad and Specific Categories of Distress/Stress/Anxiety

Of the four incidents of distress/stress/anxiety represented by the broad category of personal adjustment to HIV/AIDS illness, three were further described by the specific category of loss of control and one by life change. The specific category of life change was documented in the data as follows: “This admission, (diagnosis) and decision to retire has caused client anxiety due to adjustment of changes in his life” (client code 25/Referral 1). It was documented that this client had been employed as a teacher until his current illness and had held hopes of returning to work.

Of the four incidents of distress/stress/anxiety due to clinical intervention, three were represented by the specific category of surgery. Of these, two were attributed to the clients’ post-operative condition that included pain and problems with a newly inserted portacath. One client who was due to have a splenectomy was anxious pre-operatively, the data stated “Client was anxious pre-op, but aware of limited treatment options” (client code 35/Referral 2). The remaining incident was attributed to an investigative procedure where a client was anxious and tremulous on examination and refused tests or investigations.

Other incidents of distress, stress or anxiety were attributed to the state the client was in at home prior to admission to the HIV/AIDS Unit, on admission to hospital or on discharge from hospital. The contributing factors were not directly identified on the CNRF. It was documented that the client who was anxious about discharge was given a gate pass (leave) from the HIV/AIDS Unit rather than discharge so he could return to the ward if he was unable to manage at home. Of the 27 incidents of the clients’ distress, stress or anxiety, there was no further direct information given for six.

4.7.1.3 Grief Issues

For the purpose of the study, the specific comments which related directly to the 18 incidents of grief amongst all referrals were limited to the broad category of Death (100%) refer to Figure 4.32.

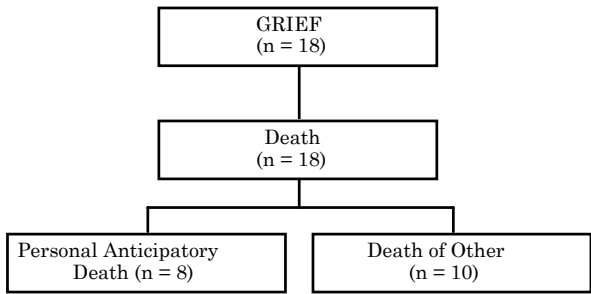


Figure 4.32 The Broad and Specific Categories of Grief

The ten incidents of grief were related to the death of others included three that were related to friends, two to partners, and one each to family members, a significant person and multiple bereavement. One client was encouraged to grieve. An example of one incident referring to the loss of a partner follows: “Recent loss of two significant people in his life ‘→’ partner of 25 yrs ‘+’ previous partner of 17 yrs” (client code 73/Referral 1).

From the eight incidents concerning personal anticipatory grief, two clients expressed a wish of where they would prefer to die, one stating “hospital” and one stating “home”. Of the remaining incidents, one client was upset by his poor prognosis and one transgender client reported that she had ceased her oestrogen medication. One client with presumptive HIV encephalopathy who was also grieving the loss of friends, acknowledged that his illness was terminal, and that he did not wish to be informed of his condition. The data said “Client states he prefers not to know how affected his brain is and

prefers to have ‘↓’ concentration so as not to ponder re his grief and prognosis” (client code 41/Referral 1).

4.7.1.4 Non Compliant/Uncooperative”

The broad categories which related directly to the 17 incidents of “non compliant/uncooperative” amongst all referrals were as follows: Clinical Intervention (8 incidents or 47%); Hospitalisation (3 incidents or 18%); and Nil Further Explanation (six incidents or 35%) (Figure 4.33).

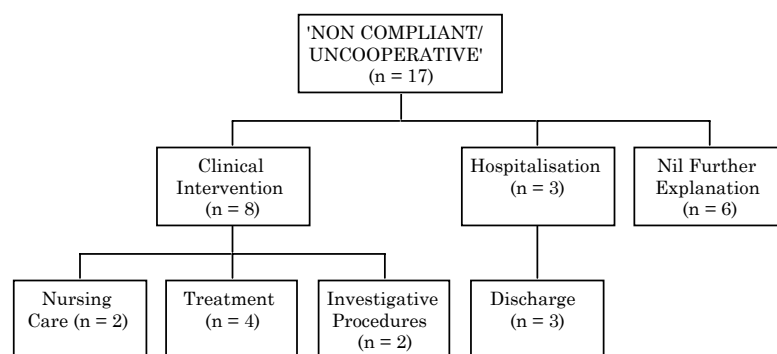


Figure 4.33 The Broad and Specific Categories of ‘Non-Compliant/Uncooperative’

Of the eight incidents described as being due to clinical intervention, two were represented by the specific category of nursing care with one client being “uncooperative” with mouth care and pressure area care and another only accepting limited community nursing contact. Of the two incidents represented by the broad category of clinical intervention, two clients did not wish to submit themselves to investigative procedures. One was stated to be “non compliant” with investigations of which one was an arterial blood gas test and the other documented incident was as follows: “Unwilling to have EEG to investigate ?fitting. Not willing to have any other investigations” (client code 42/Referral 2).

Of the remaining four incidents related to clinical intervention that were described by the specific category of treatment, three referred to medication and one to diet. These included one client who did not wish to follow advice regarding his sliding scale insulin regime or diabetic diet. Other incidents referred to PCP prophylaxis, anti-convulsants and MAC prophylaxis medication.

4.8 The Requests Made of Community Nurses on Referral

Requests made by the HIV/AIDS Unit discharge planner to the community nurse were documented on the CNRFs. The incidence of identified requests amongst all clients, all referrals and initial referrals will now be presented.

When all clients are considered (n=73), the majority of requests made to community nurses were emotional support (96%), monitor symptoms (95%) and home assessment (94%). These were also by far the most common requests amongst all referrals and initial referrals. Other more common requests on the basis of clients were to provide equipment (19%), fill the client's dosette box (18%), support the client's carer (12%) and provide terminal care (11%).

When all client referrals are considered (n=171), there were a total of 658 requests of community nurses. The remaining most common requests were to fill the client's dosette box (12%), liaise with the client's other health care worker(s) (11%), encourage autonomy (10%), assist the client's carer (9%), provide equipment (8%) and to support the client's carer (6%) (Figure 4.34). Additionally, community nurses were also requested to assist and/or support clients' carers to manage enteral/nasogastric feeds, fill dosette boxes, and administer IV, intramuscular and subcutaneous medication.

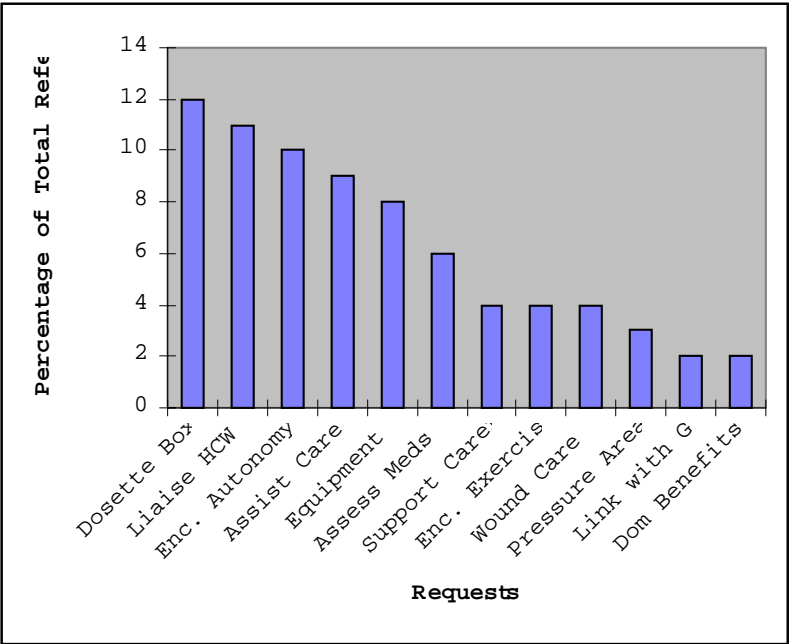


Figure 4.34 The Requests Made to Community Nurses Amongst All Referrals (n=171), Emotional support = 96%, Monitor symptoms = 95%, Home assessment = 94%, Other = 30 incidents. Liaise HCW = liaise with the client’s health care worker(s), Enc. Autonomy = encourage autonomy, Assess Meds = assess the client’s ability to take the prescribed medication, Enc. Exercise = encourage the client to exercise, Pressure Area = pressure area care, Link with GP = link client to a local General Practitioner, Dom Benefits = assist client with domiciliary benefits application.

When only initial referrals of clients are considered (n=49), there were 205 requests of the community nurses. The most common remaining requests were to monitor symptoms (98%), provide emotional support (98%) and perform a home assessment (96%). The next most common requests were to provide equipment, liaise with the clients’ health care worker (each 16%) and to fill the client’s dosette box (12%) (Figure 4.35).

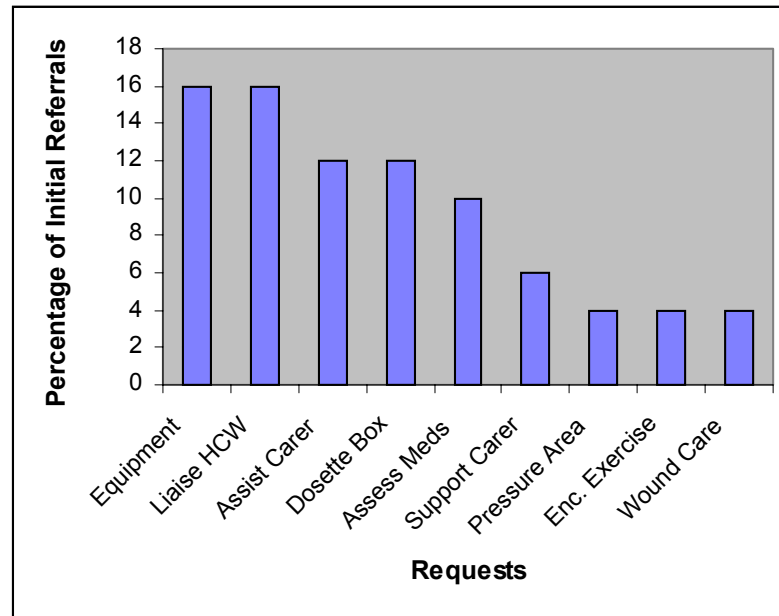


Figure 4.35 The Requests Made to Community Nurses on Initial Referral

(n=49) Monitor symptoms = 98%, Emotional support = 98%, Home assessment = 96%, Other = 41 incidents. Liaise HCW = liaise with health care worker(s), Assess Meds = assess the clients ability to take the prescribed medication, Pressure Area = pressure area care; and Enc. Exercise = encourage the client to exercise.

4.9 Conclusion to Results

The documented demographic, clinical and psychoemotional aspects of the clients have been revealed. Their mean age on referral to a community nurse was 39 years. The majority lived either with a partner or alone, and was deduced to be homosexual. Around the time of hospitalisation, the most common symptom experienced was pain, the most common condition was oral candida and the most common psychoemotional variable was depressed mood which was related to the physical effects of HIV. The most common requests made of community nurses were emotional support, symptom monitoring and home assessment.

CHAPTER 5

DISCUSSION

5.1 Introduction

In this chapter the demographic, clinical and psychoemotional aspects of clients and the requests of community nurses (as presented in Chapter 4) will be discussed. These aspects will be discussed broadly in relation to the purpose of the study (Section 1.5) with regard to the four research questions, the literature, some contemporary issues and the community nursing role.

5.2 The Demographic, Clinical and Psychoemotional Aspects of Clients

The first research question is addressed using the demographic, clinical and psychoemotional aspects of clients identified in the current study.

5.2.1 The Clients' Demographics, Home Environment and Lifestyle

According to statistics at the time of the study, the sample represents 14% of all deaths following an AIDS diagnosis in NSW during 1993 to 1995 ($n = 534$), (Section 2.4.1). The gender, sexuality, country of birth and age of the sample were similar to people known to have died following AIDS both during the study period and more recently. These findings were also similar to those found in the HIV Futures Report II where 924 Australian PLWHA were surveyed in 1999 (Grierson, Bartos, de Visser & McDonald, 2000). In addition, the high numbers of clients in the sample who resided within the eastern and inner west suburbs of Sydney (Section 4.2.2 and Section 2.6.1) reflect the known demographics of PLWHA in Sydney at the time of the study. This indicates that although it may be difficult to

generalise results, clients in this study appeared to be fairly representative of the HIV/AIDS community as a whole and were representative of PLWHA who died during the period of the study. It could also be postulated that this reflects that the community nursing service was well utilised by PLWHA, as evidenced by the 171 referrals of 73 clients.

The client's gender will effect their experience of HIV/AIDS. Although they only represented 5% of the sample (Section 4.2.1), the incidence of women with AIDS continues to increase (Section 2.4.2). Women have specific psychosocial and physiological issues which may result in multiple daily responsibilities and stressors (Rose, 1993). These issues may be due to womens' potential for or existing pregnancy; the fact that they are often carers and/or mothers - perhaps of HIV-infected children (Mijch et al., 1997; Rose & Clark-Alexander, 1996); or that women tend to put other peoples' needs before their own (Carnegie & Rutter, 1992; Rose & Clark-Alexander, 1996).

Australian authors, Mijch, et al. (1997) found that, in comparison to homosexual men, women are less likely to have access to supportive groups where they can share and identify with other women who have HIV. As a result, they are more likely to feel isolated and alienated by their illness. A cohort of 84 women who participated in the Australian HIV Futures Study conducted in 1997 (Ezzy et al., 1998) identified that women were found to be significantly less likely than men to be taking any prophylaxis for opportunistic infections. Almost two thirds of the women stated they were in a relationship and they were significantly more likely than men to believe that no one would want a relationship with someone who was HIV positive.

There is a need to further research the natural history of HIV infection in women (Krause, 1993; Rose, 1993) as well as their psychosocial, cultural concerns (Rose, 1993; Rose & Clark-Alexander, 1996) and epidemiological profile (NCHECR, 1994a). There is also a need to understand, identify and address the gender-specific needs of male and transgender clients.

It is not known why the sexuality of 68% of clients was not specifically stated on referral (Section 4.2.3). No client was documented as being heterosexual. It is possible the community nurse may have known the client's sexuality and it was unnecessary for the discharge planner to repeat this information. While this limits the interpretation of the data, it was deduced that 32% of these clients had homosexual contact at some stage and it could be postulated that a large proportion of the remainder was homosexual. This would be consistent with the Australian figures of the exposure category of death following AIDS which has remained at around 84% for male homosexual or bisexual contact since the study period (Section 2.4.5). In addition, clients documented as having a partner of the same sex, may not necessarily identify themselves as homosexual.

There was no indication in this study as to whether clients were of ATSI background. The exclusion of ATSI origin information in health and health related a data collection has been identified as a significant problem (NSW Health, 1999). It is possible that this information was provided to the community nursing service verbally on referral. It would be important to obtain this information since it has implications for health service assessment and delivery. The health of people of ATSI background is far worse than other Australians (National Health Strategy, 1992) and it is important to involve the community and other organisations in planning and providing culturally sensitive care (South East Sydney Area Health

Service, 1996). Of particular concern is the higher rate of heterosexual transmission of HIV amongst women when compared to the general population (Section 2.4.2). It is important that the Aboriginal community has access to Aboriginal health workers who have been educated in the areas of HIV/AIDS. Community nurses need to develop and expand links with other service providers of ATSI people and work collaboratively with them and the community to achieve positive health outcomes in a way that is acceptable to them.

The HIV exposure categories of clients in the sample could not be compared to the literature (Section 2.4.5) as this information was not available in the examined data. However, the identified and deduced sexuality (Section 4.2.3) gave some indication that homosexual or bisexual contact was likely to have been the most common. Although the client's employment status or housing situation was also not specifically stated in the study data, it is known that almost half were reliant on government benefits for at least some time during the study period (Section 4.2.3). This is slightly less than for NSW respondents to the HIV Futures 1 study (ARCSHS, 1999) (Section 2.6.1). The HIV Futures Study II (Grierson et al., 2000) identified over half of their sample of Australian PLWHA (n=924) relied on a government pension or benefit as their main source of income, with almost one third living below the poverty line. Almost two thirds had ceased work due to an HIV/AIDS-related issue, the most common being stress, depression, anxiety and lethargy. With its relation to overall health, it is clear PLWHA today still experience the negative effects of financial insecurity.

Substance use was not reliably documented in this study. This is demonstrated by the absence of information for the majority of clients (Section 4.2.3), and ambiguous and subjective documentation for other clients, (for example, 'heavy' or 'social' alcohol use). It may be that 'heavy' alcohol intake was above the recommended amount and had a negative effect on the client's life. There was, however, no documentation on any such negative effects, the client's assessment of their drinking or any offered intervention. The majority of clients most likely did not volunteer past or recent recreational substance use, rather than there being no history at all. It is possible health care workers and the clients did discuss this area but it was not documented. The HIV Study II (Grierson et al., 2000) identified alcohol as the most commonly used drug by PLWHA in their sample (n=924). When compared to the general population, alcohol consumption was similar, however tobacco use was almost doubled, as was the use of 'party' drugs, for example amyl, ecstasy and speed. Two thirds of respondents stated they had never injected drugs.

Information and any changes concerning the clients' substance use should be taken into account when formulating the community nursing management plan (Section 2.6.3). Given certain guidelines, clients who are actively taking drugs can be safely cared for in the home (Schmidt, 1992). Nurses are more able to genuinely fulfil their caring role when they have explored their own issues and able to accept the limitations and choices of their clients. This allows them to implement realistic strategies to improve or maintain the health of their clients who are using drugs (Naegle, 1994). Knowledge of nicotine use would be useful for the community nurse, particularly in monitoring respiratory health, as PLWHA who smoke are more likely to develop bacterial chest infections (Section 2.5.1.4). Although it is stated nurses should give priority to implementing strategies which assist their clients to stop smoking (Hurley

& Ungvarski, 1994), this may be an inappropriate goal for some clients.

Details regarding the contact person for the client with HIV and who they are living with (Section 4.2.2) provides the community nurse with insight into who may be the client's major social supports (Section 2.6.5). A strong social support network increases the potential for general health and well-being throughout life (Stowe et. al, 1993). Lack of social supports significantly contributes to the psychiatric morbidity of clients with HIV/AIDS (Catalan, 1995), and when compared to those in supportive relationships, socially isolated people are at greater risk of suicide (Burich & Judd, 1997; Lippmann, et al., 1993; Miller & Riccio, 1990). The HIV Futures II Report (Grierson et al., 2000) identified that the major sources of support to PLWHA in their sample (n=924) were partners, pets and close friends. Just over half (53%) reported there was no-one who gave them a lot of support. Community nurses need to be aware of available resources that aim to increase the social supports of their clients with HIV/AIDS.

Consistent with the literature (Section 2.6.5), clients in the study were more likely to be living with and/or have a designated contact person who was a friend, rather than a parent or other relative (Section 4.2.2). The strength of the support system of the HIV/AIDS client at home will be dependent upon the relationships they have with their social peers, as well as the ability and practicality of those peers to contribute to their care (Bennett, 1988). The fact that 25% of the clients in the study remained living alone is significant, given the advanced stage of their HIV/AIDS illness. This would certainly have had implications for the community nursing assessment of their home care needs. It is likely these clients were without a full time carer and may have been isolated in their home

environment and unable to access help in the case of an emergency or sudden deterioration. In some cases, the community nurse may assess the client with advanced illness as being inappropriate to remain at home. This may also have been the assessment of the discharge planner for some clients, despite their decision to return home.

It is possible that some of the identified partners (26%) and friends (14%) who were living with the clients in the study at the time of referral (Section 4.2.2) were caring for someone else, were perhaps bereaved or were also unwell. Therefore, it cannot be presumed that they took on the role of carer. This may also have been the case for the friends and partners of those clients who lived alone, as it is known that 14% of clients experienced grief (Section 4.7) of which some were related to the death of partners, friends, significant others and multiple bereavement (Section 4.7.1.3).

It is clear that the existence of family and friends does not necessarily mean the client will always benefit from these relationships. Berk and Nanda (1994) found the assistance with the personal care of PLWHA by caretakers ranged from never to always. Despite a wish to be supportive, the efforts of family and friends may be ineffective or even provide a negative experience for the client (Britton et al., 1993). Family and carers may also experience psychological reactions that impede their own health and ability to care for the client with HIV (Section 2.6.5), their needs require assessment and integration into the overall client management plan (Ross, 1997).

Lack of a telephone, although not common for clients in this study, would have caused concern to the community nurse, since it serves as a vital link between the client and the outside world and also assists the nurse to effectively communicate with and generally maintain the client at home (Section 2.6.5). Social exclusion creates misery and the presence of a stigmatising condition such as HIV/AIDS compounds the situation (WHO, 1998).

As the demographic and lifestyle issues are strongly linked to the individual psychosocial and psychoemotional effects of HIV/AIDS disease (Section 2.6.4), the community nurse needs to be sensitive to the client's issues and wishes. These are likely to be more evident within the client's home environment than in the hospital ward. Unlike the hospital environment, the nurse cannot presume that all visitors to the home are aware that the client has an illness. Clinical efforts to improve the level of social supports are especially important for clients with HIV (Kelly et al. 1993). While there is a proven link between social support and psychological status of those infected with HIV (Fleisham & Fogel 1994; Miller & Riccio 1990), further research is required in this area (Green, 1993).

Information required by the community nurse to plan effective home care includes the extent, availability and ability of the client's social support network, the relationships of the persons living in the client's home, the person appointed to act on the client's behalf in an emergency (that is, the contact person), and the necessary telephone numbers (Ungvarski et al., 1994). As only some of this information was documented in the study data, the community nurse would need to clarify unknown aspects on initial home assessment.

It is important that community nurses have an understanding of how the gender, country of birth, language spoken, age and mode of exposure to HIV impact on the experience and response of PLWHA to the various stages of their illness. Awareness of the clients' demographic details on referral, including aspects of their cultural and social dimensions, provides the community nurse with an initial overview of some individual characteristics of their clients and way of life. As the personal sociodemographic attributes of PLWHA can affect their coping behaviours (Fleisham & Fogel, 1994), this information is recognised to be an important step for the community nurse in assessing the clients' needs and planning their care in the home environment (Meeks-Festa et al., 1994). This information also assists the community nurse to assess their own needs in terms of education and professional support.

5.2.2 Clinical Aspects of Clients

With a mean CD4-cell count of 44 (Section 4.3), most clients in the study had experienced severe symptoms of immunosuppression on initial referral to community nursing services. The CD4 count was not documented for 25% of clients in this study. This is useful information, particularly on initial referral, as it indicates the degree of the client's immunocompetence. The low CD4 count of the clients on referral was an effective predictor of decreased survival time (Section 2.5.1.1) given that the sample comprised clients who died within the study period. The mean time between HIV diagnosis and death (estimated from the available data) of 6 years (Section 4.3), indicates that clients in the study experienced a rapid disease progression. This may have been related to the sampling technique used where all clients died within the study period and also, it is not known how advanced their illness was at the time of HIV diagnosis. Due to the routine intervention of effective antiretroviral therapy and viral

load testing since the study period (Section 2.5.1.1), an overview of these aspects of the client on referral would assist the community nurse to monitor their clients with HIV.

Although PLWHA experience significant stressors throughout the HIV illness trajectory, the time of AIDS diagnosis is particularly stressful, since they are confronted with the fact they have a life threatening illness (Glare, 1994). Furthermore, the clinical manifestations of HIV/AIDS have been directly associated with a deterioration in the client's quality of life (Rose & Clark-Alexander, 1996). Although the client's AIDS-defining illness was not specifically identified in the data, the most commonly occurring HIV Category C conditions documented as the client's past history gave some clues as to what the AIDS-defining conditions may have been. These were PCP, KS, CMV, MAC, cryptococcus and oesophageal candida (Section 4.3.1); and were similar to the common AIDS-defining conditions described in the literature (Section 2.5.1.2).

HIV wasting disease was not commonly documented despite 56% of clients experiencing weight loss (Section 4.3.2), nor was oesophageal candida or HIV encephalopathy. It could be postulated that the commonly identified diagnoses would have resulted in HIV wasting disease in many clients in the study with advanced illness. The finding in the literature that the HIV Category C conditions of MAC, PCP, KS, oesophageal candida, HIV wasting disease, lymphoma and cryptococcosis are associated with the highest risk of death (Section 2.5.1.1) are consistent with the current study. These conditions were found to be less common as a past history of the client on referral (in addition to CMV and encephalopathy) (Section 4.3.1), but more common as a new diagnoses or as a reason for admission

(Section 4.3.3).

Although prognostic statistics are increasingly important in determining the suitable medical management of PLWHA, they count little to individual clients with HIV infection. Clients and their families relate much more easily to an estimation of survival given in time frames of, for example, days, weeks or months (Glare, 1994). While the categorisation of HIV conditions is useful in clarifying stages of progression, it has limitations and does not reflect the health status of the individual (Section 2.3). It is important that the community nurse is aware of their client's immune function and stage of HIV illness. This knowledge will assist them to assess the needs of their client in areas such as prophylactic medication, review of antiretroviral medication, vulnerability to HIV/AIDS disease, prognosis of illness, symptom monitoring, educational needs and possible psychoemotional responses.

The high incidence of past history of HIV related clinical conditions amongst the initial referrals (75 incidents of 19 HIV Category B or C conditions amongst 49 clients) (Section 4.3.1) highlights the many physical consequences clients experienced as a result of their HIV infection prior to their referral to community nursing services. Common conditions included oral candida (29% of clients), PCP (22% of clients), peripheral neuropathy (14% of clients) and KS (12% of clients). Despite this, it is known that 16% of clients had no previous AIDS-defining illness on initial referral. However, it is possible this figure could be as high as 40%, as the additional 24% of clients who had no documented previously occurring HIV Category C illness could also belong in this category. Therefore, it is possible up to 40% of clients had no previous AIDS-defining illness on initial referral to community nursing services.

The high incidence of recent conditions at the time of referral (501 incidents amongst 73 clients) (Section 4.3.3) indicates that clients experienced a number of conditions simultaneously rather than in isolation. This was clearly confirmed in the study from the cross tabulation results of the most commonly occurring clinical variables (Section 4.4).

Conditions stated as a new diagnosis or reason for admission did not necessarily include all recent conditions experienced by the client. Other conditions may have occurred and been treated in the community (for example by the local doctor or specialist) and not documented on the CNRF. As clients with advanced HIV/AIDS can experience multiple pathologies, these findings may be incidental or asymptomatic and not the reason for admission. Some non-HIV Category B or C conditions may be related to the client's HIV infection (for example, herpes simplex virus, ulcers, herpes zoster, ear disorder, fall or injury, anaemia) or treatment (for example, drug allergy or intolerance, anaemia). However, as PLWHA can also experience problems unrelated to HIV, the community nurse should not presume all physiological events are due to HIV. The HIV Futures Report II (Grierson et al., 2000) identified 25% of their sample of 924 PLWHA experienced a non-HIV related health problem. These included hepatitis C, asthma, hepatitis B, arthritis, respiratory illness and diabetes.

Major health conditions affecting clients in the sample were oral candida, MAC, anaemia, drug intolerance and CMV infection. They each had a high incidence as part of the client's past history, current new diagnoses, or as the reason for admission to the HIV/AIDS Unit, and also as recurring conditions amongst individual clients. These conditions are examples of

common, long standing problems that appear to be poorly controlled amongst the clients with advanced HIV/AIDS disease. Each of these conditions has implications for community nursing care.

It seems likely that, in most cases, oral candida (32% of all clients) would have been a new diagnosis rather than a reason for admission. Community nurses would need to closely monitor the severity of oral candida in their clients as it can become resistant to treatment and lead to the serious complication of oesophageal candida, which is difficult to eradicate (Section 2.5.1.3). Despite the high prevalence of oral candida amongst the clients in the sample, it appears that its treatment and management was sufficient to prevent the development of oesophageal candida in most cases.

The documented diagnosis of MAC is significant, as it was the most common HIV Category C illness identified as the client's new diagnoses or reason for admission to the HIV/AIDS Unit (27% of all clients). MAC is also related to anaemia, another commonly identified new diagnosis or reason for admission; as well as to the common symptoms of pain, fever, diarrhoea and weight loss (Section 2.5.1.3). Community nurses are able to assist clients by offering advice and support with regard to medication regimes (curative and prophylactic), encouraging adequate nutritional intake, offering symptomatic relief where possible and providing home and personal assistance in order to counteract the negative aspects of MAC. Hospitalisation is often required for review of the cause of anaemia and also the administration of blood transfusions. Anaemia may result in the common symptom of lethargy (Section 2.5.1.3) and it can limit the client's ability to undertake enjoyable activities and to remain independent. Such limitations to autonomy were identified in the study as attributing to the

client's depression (Section 4.7.1.1).

The development of an allergy or intolerance to medication can be a serious problem for PLWHA since, in addition to the adverse effects, it has implications for the treatment of the condition for which the medication was prescribed. Consistent with the literature (Section 2.5.4), drug intolerance of clients in the study was most commonly caused by sulphur drugs, penicillins and dapsone (Section 4.3). Medication is vital in the primary and secondary prophylaxis and treatment of HIV/AIDS disease and bactrim (a sulphur drug) and dapsone (generic name allopurinol) are first and second line treatments for PCP, the most common cause of mortality in untreated PLWHA (2.3.1). Drug intolerance may also have contributed to the high incidence of anaemia and skin rash problems experienced by the clients. It is unfortunate that hospitalisation due to the iatrogenic conditions of drug intolerance and insertion/review/repair/removal of a long-term venous access device (each occurring in 16% of clients) were so prevalent amongst the clients in the study (Section 4.3.3). Clients with allergies or intolerances to medication were re-referred to community nurses more times during the study period than clients with no history of this.

The area of therapeutic interventions for HIV/AIDS is where most change has occurred since the study. It is possible that the current incidence of allergy or intolerance to medication in PLWHA may be even higher for the currently prescribed combinations of antiretroviral medications, often poorly tolerated by clients. Classes of current antiretroviral treatments include protease inhibitors which can cause lipodystrophy (fat redistribution) and non-nucleoside reverse transcriptase inhibitors, which can cause rashes, neurological disturbance and cross resistance

(Batrouney, MacMahon & Murphy, 1999). Melbourne, Abbaticola, Rona and Fisher (1998) found that 81% of their sample of clients on ritonavir (n=74) discontinued treatment due to resultant nausea, vomiting and diarrhoea. Side effects were experienced by over half of the sample of Australian PLWHA (n=924) in the HIV Futures Report II (Grierson et al., 2000) with diarrhoea and nausea also the most common. Health care workers treated for post HIV exposure prophylaxis have also experienced these symptoms in addition to headache, myalgias and arthralgias (Wang, Panlilio & HIV PEP Registry Group, 1998).

Nurses have an important role in monitoring the side effects of all medications taken by their clients (Schmidt, 1992). It is the responsibility of the community nurse to be knowledgeable of the various side effects and interactions of the many current combinations of medications prescribed to PLWHA by treating medical officers. This is recognised as a complex task due to new medications and combinations being prescribed and trialed; the common practice of polypharmacy in PLWHA; and inadequate knowledge of the risks of toxicity, interactions and the mechanism of increased hypersensitivity (Carr & Garsia, 1997; Miller & Riccio, 1990). It is important that the complete medication regime of clients is reviewed regularly (Bennett, 1988). Community nurses are likely to benefit from close liaisons with pharmacists to ensure access to current information that allows them to effectively monitor, support and educate their clients and their nursing peers.

CMV disease (excluding CMV retinitis) was a common previously experienced condition (21% of all clients) in addition to being a common new diagnosis or reason for admission to the HIV/AIDS Unit (15% of all clients) amongst clients in the study. These figures are likely to be higher when CMV retinitis is also considered however the study did not indicate concordance of these variables amongst the clients. The treatment of systemic CMV disease is related to anaemia, drug intolerance and insertion/repair/review/removal of a LTVAD and these are commonly identified symptoms, previously occurring conditions, new diagnoses or reasons for admission and also recurring conditions. Systemic CMV infection often results in gastrointestinal symptoms and it was the most common illness causing the symptom of pain in these clients (Section 4.3.2.1).

In addition to assessment and symptom monitoring, diagnosis of CMV often requires the community nurse to be proficient at administering IV medication in the home environment. Clients with systemic CMV were usually treated with IV ganciclovir (2.5.1.3) three times a week for the rest of their life (MIMS, 1995) through a LTVAD, and this was the most commonly prescribed IV medication of clients in this study (Section 4.5). Care in the management of ganciclovir is of particular importance as it is treated as a cytotoxic drug, and nursing practice must comply with the occupational health and safety standards outlined by the NSW Workcover Authority (1995) which were endorsed by the NSW Department of Health Circular 95/49 issued in June 1995.

IV foscarnet was the second choice of treatment for CMV disease. It was required to be given over a two hour period, five to seven days a week with thrice weekly pathology monitoring. Foscarnet was administered concurrently with hydrating fluids to minimise its toxic effects to the kidneys (MIMS, 1995). This regime would have been far more restrictive for the client's lifestyle than ganciclovir. With intolerances to ganciclovir and foscarnet and infection of LTVADs being common, the community nurse had an important role in ensuring their safe administration and management in the home as well as monitoring side effects and liaising with the prescribing medical officer to review dosage.

Chest infection, KS and cryptosporidia infection were also commonly documented in this study as a new diagnosis or reason for admission to the HIV/AIDS Unit (Section 4.3.3). Chest infection and cryptosporidia could result in the client experiencing the debilitating, distressing and commonly occurring symptoms of dyspnoea and diarrhoea. KS and cryptosporidia were also commonly identified as previously occurring and recurring conditions, and as such were a long-standing problem and appeared to be poorly controlled amongst the clients. The community nurse can assist the prevention, early detection and management of these conditions by regular symptom monitoring. KS can be particularly distressing for PLWHA as it may exacerbate existing psychoemotional and psychosocial problems, through causing disfigurement (Section 2.5.1.5). Skin rash was also a common new diagnosis or reason for admission that was likely to have caused client discomfort. It may be that the cause of skin rash in some cases was related directly to the level of immunosuppression or as a reaction to medication (Section 2.5.1.5).

The clinical diagnosis of depression, the review of a LTVAD and CMV infection as new diagnoses or reasons for admission were found to be more common amongst the initial referrals than all referrals (Section 4.3.3). It may be that they were conditions that the introduction of community nursing services was particularly preferable, possibly due to the care of the long term venous access device site, home IV therapies, or concerns regarding the impact of depression.

Anaemia, falls or injury, and drug intolerance were more common when all referrals were considered rather than only initial referrals. This indicates that they occurred more commonly after community nursing services were commenced. This was perhaps because these conditions were more likely to be experienced by the client as their deterioration progressed.

PCP was the client's most common previously occurring HIV Category C condition (Section 4.3.1). Presumptive PCP refers to suspected cases of PCP which responded to treatment but were not confirmed on pathological examination of induced sputum samples (Smith & Pigott, 1997). Adding total cases of presumptive diagnoses of PCP to confirmed diagnoses, the overall incidence would have equalled oral candida as the most common previously occurring condition amongst clients on referral, and the fifth most common new diagnosis/reason for admission amongst all referrals (Section 4.3.3).

The incidence of PCP decreased significantly at the time of the study due to the success of prophylactic medication introduced when the client's CD4 count was below 250 (Smith & Pigott, 1997). Some of the clients allergic to bactrim in the study could have undergone desensitisation regimes (Smith & Pigott, 1997) which allowed them to tolerate this preferred prophylactic

medication. PCP was not identified as a major new diagnosis or reason for admission or recurring condition during the study, despite its high incidence in the client's past history (Section 4.3.1), indicating that in most cases, primary and secondary prophylactic interventions were successful. Prophylaxis has resulted in the client's first AIDS-defining condition often occurring when their immunodeficiency is more advanced, being more likely to be MAC or CMV retinitis (Marriott & McMurchie, 1997). However, as 50% of new AIDS diagnoses are currently around the time of HIV diagnosis (NCHECR, 2000b) (Sections 1.4.1 and 2.5.1.2), a reversal of this trend could occur.

Two important roles of the community nurse with regard to PCP are to monitor the client's ability and willingness to take prophylactic medication; and to assess for signs and symptoms, (for example fever and dry cough) (Section 2.5.1.4), in susceptible clients who have a CD4 count below 250. The monitoring of medication would include the education, support and encouragement of clients to continue their prophylactic medications, and facilitation of timely medical review where intolerance was an issue so this could be addressed and resolved as quickly as possible.

Although not a common finding in the study, HIV encephalopathy (Section 4.3.3) is common in the literature (Section 2.5.1.8). As 32% of clients experienced a cognitive deficit (Section 4.3.2), it is possible that many clients in the study had HIV encephalopathy that was not diagnosed or reported. According to the literature (Section 2.5.1.8), it is also possible that community nurses identified a cognitive deficit in clients who did not have this documented on the CNRFs. There was no indication given of how the clients were affected by their cognitive deficit. This information would have assisted the community nurse to assess the client's functional

abilities and level of safety in the home setting.

Neurological symptoms may have an insidious onset and be difficult to differentiate from fatigue or depression, or be complicated by coexistent depression (Section 2.5.1.8) and/or substance use (Schietinger, 1986). As early identification and treatment is often successful in resolving lesions and symptoms of the central nervous system, their immediate assessment, diagnosis and treatment is crucial to the well-being of the affected client (Jones et al., 1997; Lander & Reid, 1991). Clients and their carers should be aware of the neurological symptoms to report (Gary, 1991). It is important that the community nurse has the skills to identify and respond to any neurological sign and symptom in the client with HIV/AIDS (Gary, 1991; Lander & Reid).

HIV encephalopathy presents particular challenges to the community nurse when clients present with ADC. This often results in health care staff requesting specialised assistance with the management of affected clients (Grassi et al., 1995). The role of the community nurse includes the provision of supportive care; clinical assessment; symptom monitoring and management; prevention of complications; home assessment to reduce falls; client and carer education; and family assistance (Bennett, 1988; Gary, 1991). It is important that issues related to death, wills and life prolonging treatments are discussed earlier in the course of HIV illness while the client is capable of formulating and expressing their views (O'Dowd, 1995). The community nurse may direct the client and family, as appropriate, to the importance of addressing these issues prior to the development of dementia, however decisions in these area may change over time.

Despite its prevalence in 27% of all clients as a previously occurring condition (Section 4.3.1), it is interesting that HSV (Sections 2.5.1.3, 2.5.1.5 and 2.5.1.12) was not identified as a common reason for admission or as a recurring condition. This could be due to the success of the treatment, or that its incidence was overlooked, under reported or overshadowed by the presence of other more serious and immediate problems. The community nurse needs to monitor HSV as part of the client's physical assessment, and encourage medical review and treatment if outbreaks become frequent or severe. It is also the role of the community nurse to educate clients and carers regarding the prevention of secondary infections or the spread to other sites, for example eyes, or to other people.

Hepatitis as a past history in 21% of clients (Section 4.3.1) may alert the community nurse to review pathology results regarding current liver function and carrier state. There was not a high incidence of severe liver disease or injecting drug use identified amongst the clients in the study, indicating that the majority of clients most probably experienced uncomplicated episodes of hepatitis A or B. An increase in the numbers of IDUs developing HIV/AIDS could lead to an increase in the incidence of liver complications amongst PLWHA in the future due to chronic hepatitis C infection. As HIV medications can be toxic to the liver (Section 2.5.1.3), any pre-existing liver disease may lead to intolerance of these medications. It is the community nurse's responsibility to monitor the client for the development of possible complications.

The most common symptoms amongst all clients were pain (62%), fever (59%), lethargy and weight loss (each 56%) (Section 4.3.2). There was no obvious difference between the incidence of symptoms amongst initial

referrals and all the clients in the study or those identified in the literature (Section 2.5.3). Suffering is related to all symptoms and it is clear that their management is integral to the client's sense of control (Bennett, 1988). This is a role shared by the medical and nursing profession (Zeller et al., 1993). The community nurse has a vital role in symptom management (Gary, 1991) and this may require frequent visits (Schietinger, 1986). Requirements for the clients and their carers or families to successfully cope with life in the presence of symptomatic HIV disease include the management of symptoms and therapeutic regimes in addition to adaptations which may involve changes in self concept, roles and relationships. Although management of the multiple symptoms frequently found in PLWHA is complex (Newshan & Wainapel, 1993), significant benefits to the client and their quality of life can be achieved through knowledgeable symptom assessment and appropriate intervention (Glare, 1994). Zeller et al., (1993) recognised that few studies had been undertaken in symptom management of PLWHA and recommended this as a priority area for clinical nursing research.

The symptoms of pain, fever, diarrhoea, cough, dyspnoea, weight loss, anorexia, anaemia and lethargy require particular attention. In addition to having the highest incidence amongst clients in the study, they were also the most common recurring symptoms (Section 4.3.2). Anaemia and diarrhoea were also the most common symptoms identified as a reason for admission to the HIV/AIDS Unit (Section 4.3.3). Fever, diarrhoea, cognitive deficit and cough require further investigation into their medical and nursing management. They appear to be amongst the most difficult to control because they were the most common signs and symptoms identified as an ongoing issue on referral to community nursing services (Section 4.5). As identified in the literature (Section 2.8.3), the nursing of PLWHA is often stressful. It has been identified that nurses caring for PLWHA are

more likely to experience burnout than oncology nurses (Bennett, Michie & Kippax, 1991), and that a perception of lacking personal accomplishment is a contributing factor (Bennett, Ross & Sunderland, 1996). It is important community nurses have access to professional support when faced with the challenge of dealing with clients with HIV/AIDS who have intractable signs and symptoms.

As the most common symptom identified amongst clients on referral, pain was distressing and this needs to be addressed by caring for PLWHA. The most common sites or types of pain experienced by the clients of abdominal and headache (Section 4.3.2.1) were similar to those described in the literature (Section 2.5.3.1). Community nurses need to recognise the possibility of pain caused by headaches, CMV infection, diarrhoea, odynophagia, hepatosplenomegaly, chest infection and MAC. These debilitating conditions experienced by clients were frequently identified as causes of pain (Section 4.3.2.1).

The client's perception of pain is affected by their existing physical, psychological and spiritual state, and its presence often serves as a harsh reminder of the progression of their disease (O'Neill & Sherrard, 1993). Effective pain control is likely to positively impact on the client's participation in medical investigation, treatment, nutritional intake and quality of life (Newshan & Wainapel, 1993). Unfortunately, pain is commonly under-reported and ineffectively treated (Penfold & Clark, 1992) with a major factor being inadequate assessment (O'Neill & Sherrard).

The assessment and effective management of pain should be given a priority by health care workers involved with PLWHA (Sievert et al., 1997). Despite its high prevalence in PLWHA, studies that describe the

presentation and treatment of pain, related problems and the client's experience of pain are limited (Eldridge et al., 1994; Newshan & Wainapel, 1993; O'Neill & Sherrard, 1993) and further research is recommended in these areas. Lethargy, weight loss and anorexia or reduced oral intake were common symptoms experienced by clients in the study (Section 4.3.2) and also need to be addressed by the community nurse.

It is the role of the community nurse to identify the client's level of independence as part of the home assessment and explore options to address their deficits. Interventions may include education regarding energy conservation; utilisation of the client's existing social supports; and the introduction of other community services to assist the client with activities such as physical care, meal preparation, household chores, shopping and transportation.

HIV associated weight loss can be extreme and distressing (Allworth & Bowden, 1997). Weight loss and anorexia are related to each other and of important consideration as significant loss of weight negatively impacts on the prognosis of PLWHA. As oral candida and diarrhoea were particularly associated with weight loss in the literature (Section 2.5.3.2), it is possible these common conditions were contributing factors to the weight loss of clients in the study. Weight loss remains a problem in Australian PLWHA today (Grierson et al., 2000).

As adequate nutrition is a fundamental aspect of general health and well-being and of particular significance to PLWHA (Lang, 1993), nursing assessment of the client's dietary intake is important (Bennett, 1988; Sievert et al., 1997), particularly in the outpatient setting (Bennett, 1988). Management of weight loss includes providing nutritional supplements

(Sievert et al.), addressing the cause(s), and prescribing medication to stimulate the appetite and increase weight (Allworth & Bowden, 1997). Supplementary feeding may be administered via a nasogastric tube or by percutaneous endoscopic gastrostomy (PEG) (Sievert et al.). This can lead to a significant increase in energy, protein intake and weight gain over two months, with PEG feeds being preferred by clients over nasogastric feeding (Dowling et al., 1996).

In 8% of client referrals in the study, nasogastric or enteral feeding was implemented in the home environment (Section 4.5). It is likely the clients or their carers were required to manage the feeds independently, and it is the role of the community nurse to support artificial feeds in the home. It may have been necessary at times for the nurse to liaise with the dietitian prescribing the feeds and with the treating institution when there were concerns the tube had been displaced or the client was showing signs of intolerance for example, vomiting or diarrhoea.

Summerbell et al. (1993) found that half of their sample of clients experiencing weight loss were undernourished and suggested, that while documentation of weight is useful, the body mass index (BMI) is a more accurate monitoring tool for groups of clients. Intervention in weight loss involves the diagnosis and treatment of its cause (for example opportunistic infection or malignancy) and the management of symptoms such as anorexia, nausea, vomiting and diarrhoea. As interventions initiated in the early stages of weight loss are more likely to be successful than when extreme weight loss has already occurred (Kelly et al., 1997), the community nurse should encourage interventions when weight loss first becomes apparent.

Most clients had ongoing issues that remained evident on community referral. These may have included intractable conditions because they were chronic, progressive or unable to be resolved during admission. The most common ongoing issues of palliation, fever, diarrhoea, cognitive deficit, cough, reduced autonomy, diabetes and IV therapy (Section 4.5) represent key areas where management in the home environment could be expected to present challenges to the community nurse. As such, it is important community nurses caring for PLWHA, particularly in the advanced stage of illness, are skilled and supported in these areas.

As expected from the severe immunodeficiency and the wide range of conditions experienced by clients, oral medication was the most common ongoing treatment (Section 4.5), being prescribed to the entire sample. Polypharmacy was common amongst clients with HIV/AIDS and yet another disruption to their lifestyle that frequently caused problems, evidenced by the high incidence of drug intolerance and or allergy in the study. Although the routine use of dosette boxes have been replaced by blister packs in most cases, extra large dosette boxes are still used in the care of PLWHA due to the large amount of medication prescribed.

Advanced HIV/AIDS illness is often a slow and distressing process where the client is overwhelmed by the onslaught of physical problems. This is a time when carers and significant others can become quite distressed due to the obvious deterioration of the client and their increased physical needs. At this stage, respite admission may be helpful to the client and the carers and was identified as a reason for admission for 12% of clients (Section 4.3.3).

Collaboration between the community nurse and the HIV/AIDS Unit would have been necessary in the discharge planning of these clients. Community nurses needed to be familiar with the possible causes and management strategies for the many chronic symptoms experienced by clients with HIV/AIDS. It is likely that medication regime's were reviewed as it became clear the goal of care was palliation. With the changes HIV/AIDS heralded (Section 2.8.1), community nurses caring for the clients in this study would have been at the cutting edge of palliative care practice, as well as the innovative interventions offered to PLWHA in the home environment. It is important that clear guidelines exist for the management and maintenance of all interventions. Flexibility and coordination of services are particularly required for new practices. Decisions made by health care workers, as client advocates, need to be balanced between maintaining a safe standard of care, and the clients quality of life and ability to make informed choices (Lucey & Turbitt, 1992).

The impact the community nurse could have had on reducing the level of the client's hospitalisation was unable to be determined by this study. Although some clinical assessment and treatment interventions may be implemented in the home or as an outpatient to avoid admission to the HIV/AIDS Unit, there are other considerations. These include the:

- ◆ Assessment of the home environment and the availability of carers.
- ◆ Ability of the client to tolerate home treatment or outpatient visits.
- ◆ Level of services available in the home, for example home visits by treating doctors, physiotherapists and a twenty four hour on call nurse.
- ◆ Need for respite by the client or their carers.

Furthermore, as identified in the study, it is common for other conditions to coexist. Each individual client needs to be assessed individually and

holistically to determine the need and benefit of hospitalisation. Consequently, avoiding or reducing hospitalisation for these clients is far more complex than exploring other ways of implementing interventions for presenting conditions.

5.2.3 Psychoemotional Aspects of Clients

The relationship the community nurse develops with the client is important in their understanding of the characteristics of the client's personality and lifestyle. Rapport assists them to identify psychological and psychiatric changes at an early stage and facilitate early assessment and intervention (Section 2.8.3). While it is important to distinguish between the psychological, psychiatric and organic causes of signs and symptoms, this can be difficult in PLWHA due to similarities in some presentations (Sections 2.5.1.8 and 2.5.2.1). Other complicating factors may be concurrent causes, changing signs and symptoms, underlying psychiatric disorders and premorbid personality and lifestyle characteristics (Miller & Riccio, 1990; O'Dowd, 1995).

In comparison to non-HIV clients referred to liaison psychiatry services, an Italian study (Grassi et al., 1995), found that there was a higher prevalence of adjustment disorders related to illness, depressive disorders and dementia amongst clients with HIV. The study found that HIV clients had a greater insight into the seriousness of their condition compared to other psychiatric clients. As the impact of HIV illness was so strong, they were more likely than those with other physical conditions to actively seek psychological assistance to deal with issues related to loss, isolation, rejection and death.

Another important consideration for PLWHA is the assessment of whether substance use, distress or depression may lead to risky sexual activity (Kelly et al. 1993). Understanding the psychosocial reactions that HIV evokes both in clients and the community offers us the choice of social advancement and personal growth (Nichols, 1985). A commitment to care which does not tolerate prejudice is fundamental to effective nursing practice (Anonymous, 1993). Ignorance is at the foundation of most prejudices, therefore strategies to increase public awareness will promote the wellbeing of clients with HIV/AIDS (Stewart et al., 1997) as well as the community as a whole (Gillieatt et al., 1992). Community nurses need to assess the psychosocial needs of their clients independently from their physiological needs (Berk & Nanda, 1994). The psychosocial aspects affecting clients with HIV/AIDS deserve to be given a priority, and nurses need to be cognizant of the emotional and social needs of their clients (Rose & Clark-Alexander, 1996).

A broad range of psychoemotional aspects were identified from the CNRFs, with depressed mood (36%), anxiety (29%), grief (14%) and 'non-compliance' and withdrawn (each 12%) being the most common amongst all clients (Section 4.7). These findings were similar to those identified in the literature (Section 2.7). With the client's mean age at death being 40 years (Section 4.3), the majority of clients in the study died at an age that would otherwise be expected to be amongst the most productive of their lives. The diagnosis of HIV followed by rapid disease progression would have compounded the stressors experienced by the client.

Depression and depressed mood was a common finding amongst clients in the study. Depression was experienced by 11% of clients as a past history (Section 4.3.1) and by 14% of clients as a new diagnosis or reason for

admission (Section 4.3.3); and depressed mood was experienced by 36% of clients (Section 4.7). Although O'Dowd (1995) believes that while PLWHA may experience sadness or grief, depression is not a normal response but a separate illness requiring treatment. Despite this, the author asserts a reactive depression or depressed mood could be considered a 'normal' response to the overwhelming consequences of HIV/AIDS disease.

The literature concerning depression (Sections 2.5.1.8, 2.5.2, 2.5.2.1 and 2.7) needs to be assessed with caution, acknowledging the difference, yet relationship between clinical depression and depressed mood. Some distinction is made in the study data when the client was said to have been diagnosed with depression. This was interpreted as clinical depression and included in the data of clinical diagnoses, although it is not certain whether these cases would meet the full DSM-IV criteria (American Psychiatric Association, 1994). There may have been clients stated to have a depressed mood who did meet the DSM-IV criteria. Some clients may have chosen not to be seen by a psychiatrist and were therefore not psychiatrically assessed. In the data analysed, there was no consistent clear indication of the severity of the client's clinical depression or depressed mood. Community nurses able to develop a good rapport with PLWHA, are in a good position to detect, assess and monitor depression in their clients.

Suicidality was not identified in the data as a current or previous issue. Omission of data cannot be interpreted as absence of these issues, so it is possible some of these clients may have had previous suicidal ideation or attempts that were not documented. Furthermore, the study data does not describe the circumstances of each client's death. In line with expected standards of care, it can be expected that clients were not known to be

currently suicidal on discharge from the HIV/AIDS Unit, as discharge in this case would be contraindicated. With depression and depressed mood being so commonly identified (Section 4.7), it is likely that some of the clients in the study thought about suicide at some time. It can also be postulated that a significant proportion those clients diagnosed as being clinically depressed would have been assessed by a psychiatrist during their admission and questioned about suicidal ideation. A high standard of management of clients with depression is reliant upon the expertise of health care workers in the evaluation of suicidality (Valente & Saunders, 1994). It is important the community nurse is aware of the signs and symptoms of depression and seeks medical assessment of their clients if they are concerned.

Interventions for distress and anxiety focus on the client's coping mechanisms, and important determinants of quality of life (Rose & Clark-Alexander, 1996). These include addressing the cause, reducing its effects on health, counselling and assisting to restore some sense of the client's control over their lives through self help strategies (Lang, 1993). Depression and anxiety remain a significant problem today. Grierson et al. (2000) identified almost one third of their sample of Australian PLWHA (n=924) had taken prescribed medication for depression and one quarter for anxiety.

As the incidence of HIV/AIDS deaths has significantly decreased since the study period (NCHECR, 2000b), it could be postulated that grief, as it relates to the recent death of significant others, may not occur as commonly in PLWHA today. However, Grierson et al. (2000) identified 75% of their sample of Australian PLWHA (n=924) had someone close to them die from an HIV/AIDS-related cause. In order for them to be of assistance

to PLWHA, it is necessary for health professionals to recognise the grief process and the particular losses of each client (Salyer et al., 1987). Counselling may assist the client express their emotional pain and work through their issues (Sherr et al., 1992) and while some clients are able to heal emotionally, others never reach the point of acceptance (Salyer et al.). It is an important aspect of the nursing role to recognise when the client is preparing for death and to initiate discussion surrounding it, as frankness in this area is of benefit to the client and their carers (Grimes & Grimes, 1995).

Fourteen percent of clients in the study were identified as being ‘non-compliant’ or ‘uncooperative’ (Section 4.7) and this was a common term used in the literature (Section 2.7.4). PLWHA may be totally overwhelmed by a complicated medication regime (Carnegie & Rutter, 1992; Schmidt, 1992) and it is judgemental and punitive to label them with the recalcitrant term ‘non-compliant’ (Gilyard Brewington, 1994) and this requires ethical consideration. These value laden terms have the effect of blaming clients for treatment failure because the regime was not followed exactly and represent the client’s relationship with their health care workers as submissive, rather than concordant in which goals are shared. This language needs to be reviewed within the context of the autonomy, collaboration, choice and negotiation that PLWHA as a group have demanded; In addition to being more acceptable to the values and expectations of contemporary clinical practice (Batrouney, 1997; Gilyard Brewington). While these terms continue to appear in the literature, the terms of adherence or concordance have become more popular.

Lack of adherence to prescribed or suggested interventions was identified as a common psychoemotional variable that remains a major issue today in

the management of HIV/AIDS illness. While respecting the client's choice, the nurse should inform them of the possible consequences (Schmidt, 1992). Nurses need to be aware that treatment of a client who is otherwise feeling well may result in the development of side effects and intolerance (Arkell, 1993) (Section 5.2.2). Grierson et al. (2000) found that 75% of their sample of Australian PLWHA (n=924) used antiretroviral therapy, however 75% of these experienced difficulties with their treatment. These included remembering to take the medication on time, organising meals around their regime, taking medication in public, transporting the medication and taking large amounts of tablets.

Nurses should not interfere with the client's choices unless there are powerful reasons for doing so (Gilyard Brewington, 1994). While adherence to interventions may be a nursing goal and seen as indicative of the nurse/client relationship, nurses need to learn to step back and accept that client's have the right to choose (Carnegie & Rutter 1992; Gilyard Brewington, 1994) in the knowledge that the outcome is not a result of their personal or professional failure.

As illness threatens the realisation of goals and activities which give people a sense of meaning in their life (Scheier & Bridges, 1995), a sense of control is fundamental to physical and psychological health, well-being and quality of life (Kelly et al., 1993; Stewart et al., 1997). Meeks-Festa et al. (1994) identified that personal acknowledgment, self direction, control, and choice were highly valued by PLWHA; and they were often challenged by their illness to do things that instil in them a sense of control and hope for their future (Kermode, 1995). The belief of PLWHA that they can influence the course of their disease (Section 2.7) is demonstrated by healthy lifestyle changes often undertaken, and is probably motivated by a

strong social organisation and the uncertain outcomes of their illness.

Grimes and Grimes (1995) state the fear of loss of independence, perhaps previously witnessed by the client in friends or lovers, can often be greater than the fear of death because the way it manifests cannot be anticipated. Rejection of recommended interventions which can tend to dominate daily activities such as polypharmacy (Section 2.8.1), continuous IV regimes or nasogastric or enteral feeds may be one of the few ways frustrated clients may exercise some control over their lifestyles (Grimes & Grimes, 1995; Ross et al., 1994). It is important that clients be assisted to regain a sense of control over their lives, HIV management and treatment strategies (Kelly et al., 1993; Stewart et al., 1997).

Adherence to medication by PLWHA is an important treatment strategy that may be encouraged through emotional support and education by the community nurse, although it is important to identify the reasons why clients do not take prescribed medication. Community nurses may encourage adherence to medications through frequent visits and the use of dosette boxes to assist the client cope with their regime (Schmidt, 1992) and this was a community nursing request identified in the study (Section 4.8). It may be advisable for the community nurse, with the permission of the client, to inform the prescribing medical officer if the reasons for the client not taking medication could not be resolved. This would alert them to the client's feelings and the increased possibility of the development of complications.

Non-adherence also occurs in areas other than medications. Some clients in the study may have chosen to return home against the advice of the health care team of the HIV/AIDS Unit. Some clients in the HIV/AIDS

Unit may have refused referral to a community nurse against the advice of the discharge nurse and other health care workers and these, of course, are not represented in the study. Acceptance of community nursing referral, although encouraged prior to debilitation, may in some cases have been delayed by the client as it was not compatible with their perception of the resumption to a normal lifestyle after discharge from hospital. Rather than being seen to promote, maintain and maximise health and autonomy; community nursing referral could have been viewed by some clients as indicative of their disease progression, future loss of independence and Inevitable debility. Referral to, and interventions by, the community nurse would always have been subject to and limited by the acceptance of the client. As part of discharge planning, nurses have an important role in promoting the client's adherence to interventions through education (Delaney et al., 1994; Ungvarski et al., 1994).

As carers and families can often be overlooked; education, advice and reassurance is required in the areas of infection control, disease progression and social support options (Scott & Irvine, 1997). Health care professionals should have a formalised plan for addressing the needs of carers (Bennett, 1988) (Sections 2.6.5). It is their role to provide counselling and education to carers and families to support their relationships, encourage continued outside interests, advocate for them (Lippmann et al., 1993) and to enable them to deal with their issues and manage their situation (Arkell, 1993). The community nurse needs to utilise a model of care which allows an effective response to the needs of the carers (Hall, 1994).

The physical care of PLWHA who are debilitated can be very difficult, and support can assist carers work through their feelings of guilt if they are unable to continue their role (Carnegie & Rutter, 1992). The community nurse has a major role in the support of carers and family of the client, and emotional support of carers was identified as a request for 12% of clients in the study (Section 4.8). It is important to monitor the carer's ability to cope at home as illness advances (Delaney et al., 1994). Respite care was the reason for admission to the HIV/AIDS Unit for 12% of clients in the study (Section 4.3.3) and this allows carers to address their own needs, and they may also benefit from attending support groups (Bennett, 1988). Moons et al. (1994) found that community nurses in their study gave as much time to addressing the needs of the carers as they did to the PLWHA. Further research is required into the relationship between family support and psychoemotional responses in PLWHA (Bor et al., 1993), and the long term effects and effective interventions of the psychoemotional responses of carers (Miller & Riccio, 1990).

Psychological support of PLWHA is part of their overall clinical management. Nurses involved in the day to day care of clients are in an ideal position to manage common psychological and social problems experienced by clients, their partners and family (Catalan, 1995). It is important nurses understand the implications of an AIDS diagnosis, how their approach may influence the client and their family at this vulnerable time, and that the processing of this information will continue after discharge from hospital (Kermode, 1995). As the client and their family work through issues related to denial, fear, anger and inevitable death, the emotional support required may be as great as the physical nursing needs (Delaney et al., 1994). Friedland et al. (1996) found that while clients were generally happy with their support in general, they requested more emotional support.

Although some influences and predictors of psychological reactions have been identified in the literature (Section 2.7) and in the study (Section 4.7.1), responses can remain unpredictable throughout the course of HIV illness. As such, nurses are often required to deal with the issues in a reactive rather than a proactive manner (Grimes & Grimes, 1995). It has been documented that clients like nurses to be warm and friendly in their approach. Interventions that may be used in responding to the client's psychological distress include reflective listening and therapeutic touch (Kermode, 1995; Moore & Appleby, 1993). Holistic nursing practices of meditation, imagery and prayer may also be utilised to assist the client's adaptive responses by finding meaning and empowerment (Meeks-Festa, et al., 1994). Grierson (2000) identified practices by Australian PLWHA undertaken to improve and maintain their health included sleep, relaxation, adhering to medication regimes, exercise, spending time with pets and taking complementary therapies.

Other highly valued activities were maintaining a positive attitude, time with significant others, creative activities and sex. Over half of the sample (n=924) used some form of complementary therapy, the most common being vitamin or mineral supplements, massage, meditation and acupuncture. There is a need for further research into the efficacy and cost of psychological interventions for PLWHA (Catalan, 1995). Research also needs to focus on further comparisons and clarification of the influence gender has on the psychoemotional responses of clients (Kennedy et al., 1995).

5.3 The Associations Between the Most Commonly Identified Clinical Aspects

The second research question is addressed by discussing the outcomes of the cross tabulations of the clients' commonly identified clinical aspects. As identified in the literature (Section 2.5), clients in the study experienced multiple and coexisting health problems. Despite many of the commonly occurring diagnoses and symptoms being clinically related to each other, no significant statistical association could be demonstrated between them in this study (Section 4.4). It could be postulated that this is due to the multiple causes for each of the client's symptoms (some of which remain undiagnosed); resulting in severe, acute, recurrent or chronic presentations. The data did not indicate how long the client had experienced individual symptoms. As with other identified diagnoses, symptoms did not occur in isolation. It is postulated another possible reason for the lack of statistical association between the most common symptoms experienced by clients in the study and the most common new diagnoses or reasons for admission to the HIV/AIDS Unit was because many of these symptoms were non-specific and clinically related to constitutional disease; for example, fever and lethargy.

Although statistical concordance was not demonstrated, there may be clinical significance of some variables most frequently experienced concurrently by clients that are not routinely acknowledged (Section 4.4.7). It is possible that the symptoms of pain, fever or diarrhoea in clients admitted to the HIV/AIDS Unit for review, insertion or removal of a LTVAD were caused by an infected existing LTVAD or the effects of CMV infection (Section 4.4.1). It is postulated the majority of clients with a LTVAD were treated with IV ganciclovir, the most common ongoing treatment on discharge from the HIV/AIDS Unit (Section 4.5). The most

common site of the presenting pain in clients with CMV, MAC, odynophagia and diarrhoea was abdominal (Section 4.4.2), the most common site amongst the sample (Section 4.3.2.1). Although some clients with skin rash on admission to hospital also experienced diarrhoea, fever or pain (Section 4.4.1), it can be postulated the cause of skin rash in some cases was related directly to the level of immunosuppression or as a reaction to medication. While depressed mood, anxiety and withdrawn state may mask or be evident in cerebral pathology (Section 2.5.1.8), no statistical concordance was demonstrated in the study between these variables and HIV encephalopathy or cognitive deficit (Section 4.4.6).

It is possible other frequently coexisting variables (Section 4.4.7) also had some clinical significance, for example, anaemia and cough, and anaemia and fever. These may have been explained by the possibility that although anaemia was the reason clients were admitted to the HIV/AIDS Unit, they were in fact pancytopenic, predisposing them to fever, respiratory infection resulting in a cough or weakness and lethargy resulting in a fall.

The complex, chronic, progressive and multi-system nature of HIV/AIDS disease (Sections 2.5.1.1 and 2.5.1.2) impacts on the nursing role, diagnoses and care plan as well as community nursing services and resources. PLWHA require regular nursing assessment. Nurses need to be cognizant of the many signs and symptoms experienced by clients with advanced HIV/AIDS illness whether or not their cause is diagnosed. Multiple pathologies exist in these clients and health care workers cannot always correctly identify the cause of signs and symptoms, even if they are consistent with the clients' known diagnosis.

5.4 Emergent Themes from the Most Commonly Identified Psychoemotional Status Aspects

The third research question is addressed by discussing the qualitative findings from the most commonly identified psychoemotional variables. As the direct cause of their incidence was not specifically stated in most cases, clear conclusions cannot be drawn.

Factors that were identified as significant to the client's depressed mood, anxiety, grief and lack of adherence were: the physical effects of HIV/AIDS illness; conflict with others; death; personal adjustment to illness; clinical intervention; and issues associated with hospitalisation or the home environment (Section 4.7.1). Despite the limited information describing the psychoemotional variables, almost all of the issues in the literature related to depressed mood (Section 2.7.1), anxiety (Section 2.7.2), grief (Section 2.7.3) and lack of adherence to suggested interventions (Section 2.7.4) could be categorised using the emergent themes from the study.

Although semantic content analysis is a more reliable and practical method, given the time constraints of the study, further use of the specific comments section and identification of factors contributing to the identified psychoemotional variables was limited by its use (Section 3.8). This was evidenced by the high occurrence of variables for which no further explanation was available. On viewing each CNRF as a whole, rather than individual variables analysed in isolation of each other, the description of the many issues related to the chronic health problems and general physical deterioration affecting the client towards the end of their life would appear to contribute to the the identified psychoemotional variables.

5.5 The Requests Made of Community Nurses on Referral

The fourth research question is addressed by discussing the most common documented requests of community nurses by the discharge planner. The most common requests of emotional support, symptom monitoring and home assessment (Section 4.8) will now be discussed.

Given the wide variety of psychoemotional variables, the emotional support of clients would have been an important role of the community nurse. The community nurses would have needed to utilise their knowledge of HIV/AIDS, palliative care and community resources in addition to counselling and interpersonal skills to effectively provide emotional support to the clients and their carers. The CNRFs documented information describing the client's psychoemotional status (Section 4.7) which would have given a detailed background for the nurse to assess their client's needs in this area and provide holistic care (Lucey, Bicknell & Burke, 1997). Some of this information was identified on content analysis (Section 4.7.1) while other information was not included in the study.

Generalist community nurses are usually routinely allocated to clients from a geographically designated area (Section 2.2). It is not uncommon for a particular community nurse to be the client's main nurse in the home environment for an extended period of time, and there is potential for them to become a trusted confidante of the client and their significant others. The development of rapport and trust is vital before emotional support can be offered. The nurse would require communication, counselling and listening skills to be able to offer some support to the client in a respectful, non-judgemental and professional manner through the difficult phases of advanced HIV/AIDS illness. As indicated by the study, the client's emotions may become intense and this can impact on their overall health,

acceptance of interventions and relationships with service providers and significant others (Section 2.7).

The role of assessing the client's psychoemotional status could have been shared with other professionals who may have included a social worker, local GP or psychiatrist. Community nurses may also have required professional support and debriefing sessions in responding to the psychoemotional aspects of their clients, particularly if they were managing a number of clients with advanced HIV/AIDS illness. As the emotional needs of PLWHA were great, volunteer services were set up for the purpose of providing support to the clients and their carers and this was commonly utilised. It is postulated the community nurses referred the clients and carers to this service during the time of the study.

Symptom management is a vital nursing role (Gebbie, 1995; Hurley & Ungvarski, 1994; Janson-Bjerklie, Holzemer & Henry, 1992; Smith & Rapkin, 1995) that involves prevention, assessment and treatment (Holzemer et al., 1999). Symptom monitoring by community nurses would have been an essential skill that could become complex when the client had multiple, acute and chronic symptoms. The changes in the client's physical condition may, in some cases, be more obvious to the community nurse than it is to the client or carer themselves. The community nurse's knowledge of HIV/AIDS disease and the clients clinical history documented on the CNRF would have assisted them to provide a particular focus during their in-depth regular assessment of the more common symptoms to which the client may be predisposed. However, it is important the nurse is attuned to the client's assessment of their own symptom status as discrepancies are known to occur when subjective and objective assessments are compared (Reilly, Holzemer, Henry, Slaughter &

Portillo, 1997). When changes are detected early, it may be possible for the cause or the symptom to be treated and prevent advanced disease, complications, hospitalisation and intensive treatments. This may be facilitated through the community nurse liaising with the client's local GP or treating institution to arrange medical assessment or appropriate intervention.

Community nurses need to understand the cause, mechanism, treatment and palliation of symptoms in addition to the implications they have on the client's physical abilities, psychological status and quality of life (Holzemer et al., 1999; Linn et al., 1993; Lubeck & Fries, 1993; Valente, 1993). There is a dearth of HIV-specific symptom assessment scales (Nokes, Wheeler & Kendrew, 1994). While an HIV specific sign and symptom checklist has recently been validated (Holzemer et al., 1999), there is a need for further research in the areas of assessment, interventions and outcomes (Hegyvary, 1993). This knowledge will allow the nurse to offer interventions that effectively maximise the client's potential for comfort, independence, sense of control, ability to cope and perception of support.

As symptoms and conditions became chronic, the client's ability to maintain their autonomy can become compromised. This was exemplified in the study by the increased incidence of fall or injury as a reason for admission (Section 4.3.3); reduced autonomy as an ongoing issue (Section 4.5); and the clients' impaired ability to perform home duties, attend to their own personal care and mobilise (Section 4.6). Despite falls or injury being a reason for admission for 18% of clients in the study (Section 4.3.3), the fact it was not identified as a recurring condition indicates that community nursing interventions may have assisted in preventing further episodes in these vulnerable clients. It is also possible that some of these

clients were not discharged home again. These declining abilities increase the burden of existing carers and increase the need of home supports, particularly for clients who live alone.

Home assessment incorporates many factors, and this was one of the main requests made by the discharge planner of the community nurse on referral. A vital role of the community nurse is determining the suitability of the home environment to meeting the client's needs. By conducting a home assessment, the community nurse can assist the client in very practical ways to maximise their quality of life, independence and safety in the home environment.

It is postulated a risk assessment would have been undertaken and interventions implemented to increase the independence and safety of the client and support to carers. In achieving this, considerations would have included the layout of the home; the level of available support; limitations of carers; and the clients abilities to perform household duties, attend to their own personal care and mobilise. Interventions may have included the rearrangement of household furnishings; referral to an occupational therapist for installation of a bathroom rail and shower hose; assistance with mobilisation; provision of equipment for example a walking frame, commode chair or shower chair; and education regarding negotiating transfers, falls prevention, and energy conservation. Community nurses may assist the client with personal care such as bathing, toileting, or may share this with a carer, or refer to another service provider to assist with this and household chores. It is postulated these were activities the community nurses engaged in as the client's health deteriorated.

Despite the wide range of home based services available, these could not

replace the benefits of a significant other who lived with the client and acted as their carer. The fact 25% of the clients remained living alone (Section 5.2.1) would have caused concern to the Community Nurse as their illness progressed. It may have meant it was not a viable option for the client to remain at home in the terminal phase of their illness. Particular concerns would be related to the client's emotional status, disease process, treatment needs, level of safety, ability to self care and attend to household chores in addition to the access of their existing support network.

The challenge to the role of the community nurse is to continue to provide care and support to the client and their significant others during the terminal stages of their illness. As a multidisciplinary approach is used, the nurse would have routinely liaised with other service providers to assess, review and coordinate interventions (Section 2.8.3); and this was specifically requested for 11% of clients (Section 4.8). The community nurse does not work in isolation, but as part of a team which includes the discharge nurse, the treating institution, allied health staff, the local medical officer and volunteer organisations. As a number of services may be utilised to assist maintain the client at home, the community nurse often coordinated them so their benefit to the client was maximised.

Given the effects of HIV/AIDS, the most common requests of emotional support, symptom monitoring and home assessment appear to be appropriate to the needs of these clients. As the disease of HIV/AIDS can be erratic, regular assessments (for example, daily, weekly or monthly depending on the client's condition) are required by the community nurse so interventions can be tailored to the client's changing needs. Regular documentation of the client's status could be useful in establishing a

baseline as well as assisting community nurses unfamiliar with individual clients to effectively assess them. A purpose specific form, similar to a checklist, may assist this process.

There was no reference to spiritual care in the data examined, although this may have been addressed in the information on the CNRFs not included in the study. With its close association to the psychoemotional status of clients, the request for emotional support, in its broad interpretation, could also have encompassed spiritual care. With common new diagnoses or reasons for admission amongst Initial referrals comprising depression (80%), the review of a LTVAD (67%) and CMV disease (64%) (Section 4.3.3); in addition to 100% of clients being prescribed oral medication; the remaining common requests appear appropriate to the needs of these clients. They were equipment provision, liaison with health care workers, assistance and support of carers and filling of dosette boxes.

The documented requests of community nurses in the study does not encompass all the roles of the community nurse, as they determine their interventions based on their own assessment of the clients needs (Section 2.8.3). Furthermore, PLWHA often seek assistance from various service providers. Grierson et al. (2000) identified that services used by Australian PLWHA include treatment advice, social contact, peer support, counselling, financial advice, legal advice, pharmacy services, housing assistance, mental health services and employment assistance. It is important the community nurse is aware of the available services to assist guide or refer the client to the most appropriate resource.

5.6 Conclusion to Discussion

This chapter has discussed the findings in relation to the posed research questions. Community nursing of PLWHA with advanced illness is complex and demands a holistic approach. Interventions need to be based on the consideration of many aspects. These include the client's choices; lifestyle; social supports; physical, psychoemotional and psychosocial effects of illness; home environment; carers; significant others, available community resources; treatment needs and medical management. There remains a need for further nursing research to optimise the care offered to PLWHA. Community nurses need to liaise with other service providers and have access to professional support to assist them to provide effective care to PLWHA.

CHAPTER 6

CONCLUSION

6.1 Introduction

In this chapter conclusions drawn from the outcomes of this study will be presented. In addition, the community nursing implications from these findings will be reviewed. The study will be critiqued and recommendations for future studies will be proposed.

6.2 Broad Conclusions From the Study

The gender, country of birth and age are similar between clients in the study and people known to have died following AIDS during the study period as well as recently in Australia and New South Wales. The high incidence of residence within the eastern and inner west suburbs of Sydney also reflects what is known of PLWHA in Sydney between 1993 and 1995. Although it is difficult to generalise the findings in the study to the wider PLWHA community, these similarities demonstrate that clients in the study appear to be fairly representative of the HIV/AIDS community as a whole. The sample is significant as it represents 14% of all PLWHA known to have died in NSW during the study period. This finding also suggests the HIV/AIDS Unit that generated the community nursing referrals, and the community nursing services themselves were well utilised by PLWHA.

Although only 5% of the study clients identified from the CNRFs were female, there continues to be an increase in women with AIDS and heterosexual transmission of HIV, particularly amongst the Aboriginal community. It is important to identify specific needs of PLWHA as they relate to gender and culture. Lifestyle factors impact on the client's

response, the course of HIV illness, and its management. Although the sexuality of clients was not well documented in the study, it is postulated that the incidence of homosexual contact was around 84%, similar to current Australian figures. As 25% of the clients in the study remained living alone, the community nurse may sometimes have been the client's major support person. Consistent with the literature, clients in the study were more likely to be living with and/or have a designated contact person who was a partner or friend rather than a parent or other relative. However, it cannot be presumed that these people took on the role of the client's carer. The community nursing assessment of the willingness and ability of individuals from the client's social support network to accept a role in the the client's home management is integral to the overall home care plan. The needs of carers and family members also require assessment and integration into the overall client management plan.

The clients' socioeconomic aspects also impact on HIV illness, and with almost half of clients in the sample reliant on government benefits for at least some time during the study period, it is clear that employment and financial limitations were commonly experienced. This problem has escalated amongst PLWHA since the study period as, although survival time has increased due to improved treatments, further demands have been placed on their financial resources. The client's mean age at death was 40 years, an age that would otherwise be expected to be amongst the most productive of their lives. With only six years being the mean number of years between HIV diagnosis and death, the clients appear to have had quite a rapid decline given the high incidence of previous and current clinical characteristics.

HIV/AIDS is a complex disease associated with a multitude of conditions and issues. Major health conditions found to be affecting the clients in the sample were oral candida, MAC, anaemia, drug intolerance and CMV

infection. Each had a high incidence in the client's past history, current new diagnoses or the reason for admission to the HIV/AIDS Unit, and also as recurring conditions amongst individual clients. Chest infection, KS and cryptosporidia infection were also commonly documented as a new diagnosis or reason for admission to the HIV/AIDS Unit, as were the iatrogenic issues of drug intolerance and insertion, review, repair or removal of a LTVAD.

Most clients in the study had experienced severe symptoms of immunosuppression on initial referral. In addition to having the highest incidence amongst clients in the study, the symptoms of pain, fever, diarrhoea, cough, dyspnoea, weight loss, anorexia, anaemia and lethargy were also the symptoms that most commonly recurred. Furthermore, anaemia and diarrhoea were also the most common symptoms identified as a reason for admission to the HIV/AIDS Unit. Fever, diarrhoea, cognitive deficit and cough appear to be amongst the most difficult to control as they were the most common signs and symptoms identified as an ongoing issue on referral to community nursing services. Most clients had ongoing issues that remained evident at the time of community nursing referral. The remaining most common ongoing issues were palliation, self care deficits, diabetes and IV therapy, representing key areas where management in the home environment could be expected to present challenges to the community nurse.

Clearly, all of the above stated clinical conditions and symptoms experienced by the study clients were intractable and unable to be successfully treated or palliated due to their chronic or progressive nature. Each of these conditions has implications for community nursing care and requires further investigation into their medical and nursing management. This involves further studies focussing on the areas of prevention; the

development of assessment tools that incorporate the client's perceptions; interventions; and their outcomes.

The identified characteristics of pain experienced by clients in the study were similar to those described in the literature. The debilitating conditions of headaches, CMV infection, diarrhoea, odynophagia, hepatosplenomegaly, chest infection and MAC were frequently identified as causes of pain in this study. Other common conditions or issues identified in the study which require consideration by community nurses were PCP, hepatitis, peripheral neuropathy, skin conditions, nasogastric or enteral feeding and social isolation.

It is postulated, based on evidence from the literature and the incidence of cognitive deficit among clients in the sample, that a significant number of clients had HIV encephalopathy that was not diagnosed or reported. There was no indication given of how the client was affected by their cognitive deficit in the data examined. This information is important for the community nurse in developing a care plan. Although the literature referred to suicidality, it was not identified in the data as a current or previous issue, however this risk should be included in the community nursing assessment.

It is well documented that people with advanced HIV/AIDS experience a wide range of clinical conditions. The lack of concordance between the most commonly identified clinical variables experienced by the clients may be explained by the high incidence of chronic and concurrent conditions, constitutional disease and unconfirmed diagnoses. Although statistical concordance could not be demonstrated between these variables, their high incidence of coexistence is clinically significant.

The clinical manifestations of HIV/AIDS has been directly associated with a deterioration in the client's quality of life. A broad range of psychoemotional factors was identified from the CNRFs, with depression, anxiety, grief and non-adherence to suggested interventions being the most common. Although there were limitations in the data, the most commonly identified emergent themes of the physical effects of HIV/AIDS illness, conflict with others, death, and personal adjustment; were also consistent with the literature. In the data analysed, there was no consistent clear indication of the severity of the client's clinical depression or depressed mood. Clarification in this area would have assisted the community nurse in the development of the home care management plan. It is recommended that specific details of the clients' depression be provided on referral to community nursing services.

The most commonly documented requests of community nurses were emotional support, symptom monitoring and home assessment, and these were pertinent to the demographic, clinical and psychoemotional findings of the study. Details of these aspects offered in the CNRFs would have assisted the community nurse respond to these requests.

While the progression of HIV/AIDS can be successfully delayed in many cases today, it is not known for how long this can be maintained. Although research in the area of antiretroviral therapy continues, problems remain with drug intolerance, the development of viral resistance as well as the emergence of newly diagnosed HIV infections with multi-drug resistant strains. The AIDS crisis is not over. People with HIV/AIDS disease do not have a chronic manageable disease. Although their life expectancy has increased, many are faced with the negative effects of complex medication regimes, socioeconomic hardships and an uncertain prognosis. It is possible that people with HIV/AIDS who are currently medically stable may in the future experience uncontrolled viral replication and become as

immunosuppressed as the clients in the study and present with similar characteristics.

6.3 Implications for Community Nursing Practice

While the incidence of death caused by HIV/AIDS has decreased significantly since the study time, it is important that community nurses do not become complacent in the area of HIV/AIDS. The needs of clients with advanced HIV/AIDS are complex and present many challenges to community nurses. It is vital they continue to review their professional needs, role, interventions and outcomes to improve the standard of care offered to PLWHA in the advanced phase of their illness. Community nurses need a broad range of knowledge, skills and resources to meet their demanding roles and adequately care for PLWHA in the home.

The knowledge, skills and resources required by community nurses in caring for clients with advanced HIV/AIDS disease include:

- ◆ Awareness and identification of their own needs in terms of educational, professional and personal support including exploration of their own personal issues related to HIV, sexuality and substance use.
- ◆ Sensitivity and respect of the client's issues, wishes and choices in their management of HIV.
- ◆ Access to resources to enhance professional development, for example continuing education and quality improvement interventions.
- ◆ Access to personal support resources.
- ◆ Understanding of how PLWAs' gender, country of birth, language spoken, age, culture and mode of exposure to HIV impact on their experience and response to the various stages of their illness.

- ◆ Understanding of the implications of an HIV/AIDS diagnosis, that the processing of this information takes time and how their approach may influence the client and their family at this vulnerable time.
- ◆ Knowledge of the pathophysiology of HIV/AIDS disease.
- ◆ Clinical skills to effectively manage signs and symptoms of HIV/AIDS.
- ◆ Pharmacological knowledge including the use, actions, interactions and adverse affects of prescribed medication.
- ◆ Advanced holistic assessment skills that include physiological, psychosocial, psychological, spiritual aspects of the client.
- ◆ Clinical skills to administer and support therapies and clinical procedures in the home.
- ◆ Understanding of the client's social support networks and their abilities and limitations in providing care.
- ◆ Knowledge of available services.

The interventions required of community nurses in providing an effective holistic home based care to clients with advanced HIV/AIDS disease include:

- ◆ Advocacy for clients, carers and family.
- ◆ Holistic clinical assessment of the client to enable prevention, early detection and management of conditions.
- ◆ Encouragement of adequate nutritional intake and offering symptomatic relief where possible.
- ◆ Administration and/or support of the administration of therapies in the home for example, medication regimes, IV therapies, artificial feeds.
- ◆ Client and carer education in broad areas including infection control, nutrition, medication, energy conservation, home safety, disease progression and social support options.

- ◆ Ongoing home assessment and optimising the client's autonomy, level of safety and ability to conserve energy through exploring options to address their deficits by providing equipment or introducing other services to assist with activities such as physical care, meal preparation, household chores, shopping and transportation.
- ◆ Liaison and collaboration with, and planning and coordination of other services for example, HIV specific support services, local GP, hospital and community based allied health and nursing professionals, Aboriginal health care workers.
- ◆ Counselling and emotional support of client, family and carers which may involve the areas of depression, anxiety, grief, fear, anger, relationships and psychosocial stressors and the use of holistic nursing practices, for example, meditation and imagery.
- ◆ Personal care assistance.

Additional information to that included in the study data that might assist the community nurse assess the needs of the client on referral and formulate an effective care plan in the future includes:

- ◆ Identification of ATSI background.
- ◆ Antiretroviral history.
- ◆ Viral load measurement.
- ◆ Body mass index in addition to weight.
- ◆ Specific substance use including alcohol, nicotine and injecting drug use.
- ◆ The extent, availability and ability of the client's social support network.
- ◆ The limitations of clients known to have a cognitive deficit.
- ◆ The severity of the client's clinical depression or depressed mood.

6.4 Strengths of the Study

There is a dearth of Australian literature describing health problems of clients with advanced HIV/AIDS who are referred to community nurses. As a result of this study documentation exists describing the characteristics of clients with HIV/AIDS referred to community nurses between 1993 and 1995 within the last two years of their life. This is a study of significant pertinence as the sample represents 14% of all deaths following AIDS in NSW during the study period of 1993 - 1995. The majority of clients were from Sydney, the epicentre of the HIV/AIDS pandemic in Australia, and the study period represents the peak AIDS diagnoses and deaths in NSW and Australia. There have been no major changes or breakthroughs since the study time in the development, prevention or treatment of opportunistic infections and other conditions that occur with a severely incompetent immune system. As a result, current clients with advanced HIV/AIDS illness may experience a similar clinical picture to that identified in this study.

The descriptive and exploratory research design used is considered appropriate to the purpose and objectives of this study. The findings can be used to reveal relationships amongst the key variables, lay the foundation for further comparative, theory or hypothesis driven studies, and justify, assess or plan for improvements of the client's condition. These findings have the potential to expand the body of knowledge in the area of clients with advanced HIV/AIDS illness referred to community nurses and may lead to review and improvements in the discharge planning process and enhance the community nursing role, interventions and outcomes.

6.5 Limitations to the Study

The retrospective design of the study, lacking the manipulation of variables common to experimental designs, limits the findings to be essentially descriptive. As the data was limited to the CNRFs, which represented only part of the discharge planning process, there may have been additional important aspects that could have influenced the outcomes of this study. Furthermore, due to the time constraints, not all the information documented on the CNRFs was included in the study. Therefore, conclusions cannot be made about omitted information. The use of all available information is likely to have given a greater understanding of the demographic, clinical and psychoemotional aspects of clients, the issues they faced and the requests made of community nurses.

The requests of community nurses were only documented on the CNRF if it was known the community nurse was able to provide the service. There may have been other interventions the HIV/AIDS Unit staff or the client would have liked the community nurse to do but the service was not available. Furthermore, as community nurses perform their own assessment in the home following client referral, the study does not indicate what the actual interventions of the community nurse were following the client's discharge from the HIV/AIDS Unit.

While characteristics of clients with HIV/AIDS referred to community nurses have been identified, it is difficult to generalise the findings of this study to all clients with advanced HIV/AIDS disease. Thus the results are only an initial step in identifying the community nursing needs of this group. As the study period was 1993-1995, the findings need to be related to contemporary issues to offer a significant contribution to the area of HIV/AIDS community nursing today.

6.6 Opportunities for Further Research

Opportunities for further research were identified during this study. The findings of this study may be used comparatively to form the basis for further research into the identified aspects of clients with advanced HIV/AIDS and how this influences the community nursing role, strategies, interventions and outcomes. Examples include:

- ◆ Where cures or effective management strategies were not possible, further research may assist determine which interventions are most successful at preventing, assessing, and alleviating or minimising the effects of conditions experienced by people with HIV/AIDS. Particular focus may be given to those conditions identified in this study to be common and recurrent, for example, the symptoms of pain, fever, lethargy, weight loss, diarrhoea, cough, anaemia and cognitive deficit; and the conditions of oral candida, MAC, KS, chest infection and CMV.
- ◆ The incidence and effects of iatrogenic conditions in the treatment of PLWHA could be further explored, particularly those conditions identified in this study, for example drug intolerance and complications of LTVADs.
- ◆ The area of coexisting conditions in PLWHA could be focused on in future studies to establish trends or relationships that exist, which are not currently acknowledged.
- ◆ Studies can be undertaken to explore the more commonly identified psychoemotional aspects in the study; particularly depressed mood, anxiety, grief and non adherence to suggested therapeutic interventions; and how nursing interventions can assist these clients.
- ◆ Findings from this study can be used to develop a data base identifying the clinical, demographic and psychosocial aspects of these clients. This data base could be used to assist in identifying the nursing care needs of clients with advanced HIV/AIDS illness today.

This could be achieved by using it to review current needs, developing new CNRFs, creating assessment charts for use by community nurses and reviewing the role of community nurses

- ◆ Study outcomes could form the basis for additional research to further describe the identified aspects or test hypotheses, for example, comparison of community nursing referral forms to community nursing files; a study focussing on a specific identified clinical, demographic or psychosocial aspect of clients referred to community nurses; and comparisons of results to similar studies based in other settings
- ◆ Effective assessment tools, interventions, and outcomes of interventions for clients with advanced HIV/AIDS need to be identified by community nurses. These need to be holistic, and include the gender specific aspects of men, women and transgender clients.
- ◆ Defining the characteristics of people with advanced HIV/AIDS illness who are referred to community nurses will increase the understanding of the needs of this client group, the community nursing role, and assist community nurses plan and provide a high standard of care for their clients with HIV/AIDS.

6.7 Conclusion

Clearly, HIV/AIDS is a complex disease that significantly impacts on the individual physically, emotionally and psychosocially; those close to them; the community; the health care system and indeed, the world. The future of HIV/AIDS remains unknown and despite a decrease in HIV/AIDS and deaths following AIDS in Australia since the study period, it is apparent there is still much to be learnt about caring for PLWHA.

As a result of this study, documentation of Australian PLWHA referred to community nurses within the last two years of their life between 1993 and 1995 now exists. The research objectives have been met. There is a need for further exploration of the community nursing needs of people with advanced HIV/AIDS and effective interventions. This study begins this process.

REFERENCES

- Adelstein, S., McKnight, I., & Pethebridge, A. M. (1997). HIV and intermediate immune deficiency. In G. Stewart (Ed.). *Managing HIV* (pp. 13-14). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Adler, M. W. (1993). Emerging patterns of heterosexual HIV infection and transmission. Closing remarks. *International Journal of STD & AIDS*, 4, 363-364.
- Allworth, A. M., & Bowden, F. J. (1997). HIV and bacterial infections. In G. Stewart (Ed.). *Managing HIV* (pp. 110-112). Sydney, Australia: Australasian Medical Publishing Company Limited.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- Anderson, W., O'Connor, B. B., MacGregor, R. R., & Schwartz, J. S. (1993). Patient use and assessment of conventional and alternative therapies for HIV infection and AIDS. *AIDS*, 7(4), 561-565.
- Anonymous. (1993). Primary care teams for HIV/AIDS clients. *Nursing Times*, 89(16), 10.
- Arkell, S. (1993). Health care delivery for people with HIV infection and AIDS. *British Journal of Nursing*, 2(21), 1065-1069.
- Armitage, S.K. (1995). Continuity of care: discharge planning and community nurses. *Contemporary Nurse*, 4, 148-155.
- Australian Bureau of Statistics. (1996). *Census of Population and Housing. Sydney. Statistical Division., NSW BO1, Selected Characteristics*. Canberra, Australian Capital Territory: [On-Line]. Available: <http://www.abs.gov.au/websitedbs/d3310108.nsf/ASGC/5DD97EBF23A350014A2565140017085F>
- Australian Community Health Association. (1991). *HIV AIDS Manual for Community Health Services*. Melbourne, Australia: Bluestone Media
- Australian National Council on AIDS. (1994). Definition of HIV infection and AIDS-Defining illnesses. *ANCA Bulletin*, 18, 1-6. Canberra, Australian Capital Territory: Author.
- Australian Research Centre in Sex, Health and Society, Latrobe University. (1999) *HIV Futures Regional Reports, New South Wales. (Monograph Series no. 12)*. Melbourne, Australia: Author.
- Batrouney, C. (1997). The compliance conundrum. *HIV Herald*, 7(3), 3-7.
- Batrouney, C., MacMahon, K., & Murphy, D. (1999). The conference collection. *HIV Herald*, 9(2), [online]. Available: http://www.afao.org.au/herald_previous_5.html#sect2
- Beck, A. T., Ward, C. M., & Mendelsohn, M. (1961). An inventory for measuring depression. *Arch General Psychology*, 4, 561-571.
- Bennett, J. (1988). Helping people with AIDS live well at home. *Nursing Clinics of North America*, 23(4), 731-748.
- Bennett, L., Michie, P., & Kippax, S. (1991). Quantitative analysis of burnout and its associated factors in AIDS nursing. *AIDSCare*, 3(2), 181-192.
- Bennett, L., Rose, D., Jackson, A., & Thomas, S. (1998). Psychological and socio-medical aspects of HIV/AIDS: A reflection on publications in AIDS Care (1989 – 1995).

- Bennett, L., Ross, M.W., & Sunderland, R. (1996). The relationship between recognition, rewards and burnout in AIDS caring.
- Berk, R. A., & Nanda, J. P. (1994). Healthcare needs for patients with HIV/AIDS: construct validation. *Journal of the Association of Nurses in AIDS Care*, 5(1), 13-25.
- Bertouch, J. V. (1997). HIV and musculoskeletal disease. In G. Stewart (Ed.). *Managing HIV* (pp. 91-92). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Bingham, C. M., & Stewart, G. J. (1997). A model for our times. In G. Stewart (Ed.). *Managing HIV* (p. 2). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Bor, R., Elford, J., Hart, G., & Sherr, L. (1993). The family and HIV disease. *AIDS Care*, 5(1), 3-4.
- Boyle, M. J., Goldstein, D. A., Frazer, I. H., & Sculley, T. B. (1997). How HIV promotes malignancies. In G. Stewart (Ed.). *Managing HIV* (pp 37-39). Sydney Australia: Australasian Medical Publishing Company Limited.
- Brettell, R. P., Foreman, A., & Povey, S. (1996). Clinical features of AIDS in the Edinburgh City Hospital cohort. *International Journal of STD and AIDS*, 7, 190-196.
- Brew, B. J., Wesselingh, S. L., Gonzales, M., Heyes, M., & Price, R. W. (1997). How HIV leads to neurological disease. In G. Stewart (Ed.). *Managing HIV* (pp. 40-41). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Britton, P. J., Zarski, J. J., & Hobfoll, S. E. (1993). Psychological distress and the role of significant others in a population of gay/bisexual men in the era of HIV. *AIDS Care*, 5(1), 43-54.
- Buhrich, N., & Judd, F. K. (1997). HIV and psychiatric disorders. In G. Stewart (Ed.). *Managing HIV* (pp. 84-86). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Burns-Tisdale, S., Duprat, L., & Wells, C. (1994). Caring for people with Human Immunodeficiency Virus. Incorporating the patient's perspective. *Journal of Nursing Administration*, 24(9), 52-60.
- Cameron, M. E., & Crisham, P. (1994). The content of ethical problems experienced by persons living with AIDS. *Journal of the Association of Nurses in AIDS Care*, 5(5), 32-42.
- Carnegie, A., & Rutter, J. (1992). Growing concern. *Nursing Times*, 88(18), 40-42.
- Carney, K. L. (1990). Aids care comes home. balancing benefits and difficulties. *Home Healthcare Nurse*, 8(2), 32-37.
- Carr, A., & Garsia, R. (1997). How HIV leads to hypersensitivity reactions. In G. Stewart (Ed.). *Managing HIV* (pp. 34-36). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Carre, N., Deveau, C., Belanger, F., Boufassa, F., Persoz, A., Jadand, C., Rouzioux, C., Delfraissy, J. F., Bucquet, D., & the SEROCO Study Group. (1994). The effect of age and exposure group on the onset of AIDS in heterosexual and homosexual HIV-infected patients. *AIDS*, 8(6), 797-802.
- Catalan, J. (1995). Psychological interventions in infection with the Human Immunodeficiency Virus. *British Journal of Psychiatry*, 167(1), 104-111.
- Centres for Disease Control and Prevention. (1992) Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *Morbidity and Mortality Weekly Report*, 41(RR-17), 1-19.

- Chalmers, C., Hartwig, M., Cook, L., & O'Brien, U. (1991). The role of a domiciliary nursing service in management of AIDS. *Australian Journal of Advanced Nursing*, 8(4), 10-13.
- Chidwick, A., & Borrill, J. (1996). Dealing with a life-threatening diagnosis: the experience of people with the Human Immunodeficiency Virus. *AIDS Care*, 8(3), 271- 284.
- Coleman, C.L. & Holzamer, W.L. (1999). Spirituality, psychological well-being and HIV Symptoms for African Americans living with HIV disease. *Journal of Association of Nurses in AIDS care*, 10(1), 42-50.
- Corless, I. B., Halloran, E. J., Belyea, M. J. (1994). Nursing dependency needs of HIV-infected patients, Part 1: Methods and clinical findings. *Nursing Administration Quarterly*, 18(2), 1-10.
- Cunningham, T. (1994). Virology. In J. Gold, R. Penny, M. Ross, S. Morey, G. Stewart, B. Donovan, & S. Berenger (Eds.). *The AIDS Manual* (3rd ed.), (pp. 12-17). Sydney: MacLennan & Petty.
- De Gruttola, V., Wulfsohn, M., Fischl, M. A., & Tsiatis, A. (1993). Modeling the relationship between survival and CD4 Lymphocytes in patients with AIDS and AIDS-Related Complex. *Journal of Acquired Immune Deficiency Syndromes*, 6(4), 359-365.
- Delaney, P., Albert, D., & Meredith, D. (1994). Discharge planning and patient education. *The Lamp*, 51(4), 17.
- Dowling, S., Kane, D., Chua, A., Keating, S., Flood, P., Keeling, P. W. N., & Mulcahy, F. M. (1996). An evaluation of percutaneous endoscopic gastrostomy feeding in AIDS. *International Journal of STD & AIDS*, 7, 106-109.
- Dwyer, D. E., Adelstein, S., Cunningham, A. L., Dowton, D. N., & Merigan T. C. (1997). The laboratory in monitoring HIV infection. In G. Stewart (Ed.). *Managing HIV* (p 59-61). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Duncan, D.F. (1989). Content Analysis in Health Education Research: An introduction to purposes and methods. *Health Education*, 20(7), 27-31.
- Ehrenpreis, E. D., & Bober, D. I. (1996). Idiopathic ulcerations of the oesophagus in HIV-infected patients: A Review. *International Journal of STD and AIDS*, 7, 77-81.
- Eldridge, A. D., Severance-Lossin, L., Nicholas, P. K., & Leuner, J. D. (1994). Prevalence and characteristics of pain in persons with terminal-stage AIDS. *Journal of Advanced Nursing*, 20(2), 260-268.
- Ezzy, D., de Visser, R., Bartos, M., McDonald, K., O'Donnell, D., & Rosenthal, D. (1998). *HIV Futures Community Report, Health, Relationships, Community and Employment*. National Centre in HIV Social Research. (Monograph Series 4.)
- Feneley, M. P. (1997). HIV-related cardiovascular disease. In G. Stewart (Ed.). *Managing HIV* (p 93). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Fisher, M., & Barton, S. (1996). Oral Ganadour: A New Option for Patients with CMV Retinitis. *International Journal of STD and AIDS*, 7, 1-3.
- Fleisham, J. A., & Fogel, B. (1994). Coping and depressive symptoms among people with AIDS. *Health Psychology*, 13(2), 156-169.
- Fleiss, J. L. (1975). Measuring Agreement between two judges on the presence or absence of a trait. *Biometrics* 31(3), 651-659.
- Foley, M. E., Fahs, M. C., Eisenhandler, J., & Hyer, K. (1995). Satisfaction with home healthcare services for clients with HIV: preliminary findings. *Journal of the Association of Nurses in AIDS Care*, 6(5), 20-25.

- Foltyn, P., & Marriott, J. E. (1997). HIV and oral disease. In G. Stewart (Ed.). *Managing HIV* (pp. 67-69). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Fong, I. W., Howard, R., Elzawi, A., Simbul, M., & Chiasson, D. (1993). Cardiac involvement in Human Immunodeficiency Virus-infected patients. *Journal of Acquired Immune Deficiency Syndromes*, 6(4), 380-385.
- Frankum, B. S., & Savdie, E. (1997). HIV and renal disease. In G. Stewart (Ed.). *Managing HIV* (p. 94). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Friedland, G. (1995). Clinical care. *International AIDS Society*, 3, 6-7.
- Friedland, J., Renwick, R., & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. *AIDS Care*, 8(1), 15-31.
- Gallagher, S. (1997). Concordance: a personal view. *HIV Herald*, 7(3), 20-21.
- Gary, G. A. (1991). Peripheral neurologic complications and the Human Immunodeficiency Virus: implications for community nursing care. *Home Healthcare Nurse*, 9(6), 33-37.
- Gebbie, K.M. (1995). A holistic look at the human immunodeficiency virus pandemic. *Holistic Nursing Practice*, 10, 1-9.
- Gillieatt, S. J., Mallal, S. A., French, M. A., & Dawkins, R. L. (1992). Epidemiology of late presentation of HIV infection in Western Australia. *Medical Journal of Australia*, 157(2), 117-118.
- Gilyard Brewington, J. (1994). The AIDS epidemic: caring for caregivers. *Nursing Administration Quarterly*, 18(2), 22-29.
- Glare, P. A. (1994). Palliative care in Acquired Immunodeficiency Syndrome (AIDS): problems and practicalities. *Annals, Academy of Medicine, Singapore*, 23(2), 235-243.
- Glare, P. A., & Cooney, N. J. (1997). HIV and palliative care. In G. Stewart (Ed.). *Managing HIV* (pp. 119-122). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Gold, J., Donovan, B., & Penny, R. (1994). Clinical assessment. In J. Gold, R. Penny, M. Ross, S. Morey, G. Stewart, B. Donovan, & S. Berenger (Eds.). *The AIDS Manual* (3rd ed.), (pp. 28-43). Sydney: MacLennan & Petty.
- Grassi, L., Pavanati, M., Bedetti, A., & Bicocchi, R. (1995). Analysis of psychiatric consultations in patients with HIV infection and related syndromes. *AIDS Care*, 7(Suppl. 1), S73-S77.
- Green, G. (1993). Editorial Review: Social support and HIV. *AIDS Care*, 5(1), 87-104.
- Grierson, J. M., Bartos, M., de Visser, R. & McDonald, K. (2000). *HIV Futures II, The health and well-being of people with HIV/AIDS in Australia. (Monograph No. 17)*. Melbourne, Australia: The Australian Research Centre in Sex, Health and Society, LaTrobe University.
- Grimes, R. M., & Grimes, D. E. (1995). Psychological states in HIV disease and the nursing response. *Journal of the Association of Nurses in AIDS Care*, 6(2), 25-32.
- Hale, C. A., & Fleiss, J. L. (1993). Internal estimation under two study designs for kappa with binary classifications. *Biometrics*, (49)2, 523-534.
- Haire, B. (1997). At the coalface. *HIV Herald*, 7(3), 16-19.
- Hall, K. (1994). Peplau's model of nursing: caring for a man with AIDS. *British Journal Of Nursing*, 3(8), 418-422.

- Halloran, E. J., Corless, I. B., & Belyea, M. J. (1994). Nursing dependency needs of HIV-infected patients, Part 2: Implications for management. *Nursing Administration Quarterly*, 18(2), 11-15.
- Hanson, D. L., Horsburgh, C. R., Jr., Fann, S. A., Havlik, J. A., & Thompson, S. E., III, (1993). Survival prognosis of HIV-infected patients. *Journal of Acquired Immune Deficiency Syndromes*, 6(6), 624-629.
- Hegyvary, S.T. (1993). Issues in outcomes research. *Journal of Nursing Quality Assurance*, 5, 1-6.
- Hendriks, J. C. M., Medley, G. F., van Griensven, G. J. P., Coutinho, R. A., Heisterkamp, S. H., & van Druten, H. A. M. (1993). The treatment-free incubation period of AIDS in a cohort of homosexual men. *AIDS*, 7(2): 231-239.
- Henry, B. B., Holzemer, W.L. & Reilly, C. A. (1994). The Relationship between type of care planning system and patient outcomes in hospitalised AIDS patients. *Journal of Advanced Nursing*, 19, 691-698.
- Holzemer, W. L. (1992). Linking primary care and self-care through case management. *International Nursing Review*, 39(3), 83-89.
- Holzemer, W. L., & Bakken H. S. (1991). Nursing care plans for people with HIV/AIDS: confusion or consensus? *Journal of Advanced Nursing*, 16(3), 257-261.
- Holzemer, W.L., Henry, S. B., Nokes, K. M., Corless, I. B., Brown, M. A., Powell-Cope, G. M., Turner, J. G., & Inouye, J. (1999). Validation of the sign and symptom check-list for persons with HIV disease (SSC-HIV). [online.] *Journal of Advanced Nursing*, 30(5), 1041-1049. Retrieved from Ovid database on the World Wide Web: <http://gateway.ovid.com/rel410/server1ovidweb.cgi>
- Hoy, J. F., Marriot, D., & Gotlieb, T. (1997). HIV and non-tuberculous mycobacterial infection. In G. Stewart (Ed.). *Managing HIV* (pp. 108-109). Sydney, Australia; Australasian Medical Publishing Company Limited.
- Hospitals and Health Services Commission. (1973). *A Report on a Community Health Program for Australia*. Canberra: Australian Government Publishing Service.
- Hurley, P. M., & Ungvarski, P. J. (1994). Home healthcare needs of adults living with HIV disease/AIDS in New York City. *Journal of the Association of Nurses in AIDS Care*, 5(2), 33-40.
- Hurley, P. M. & Ungvarski, P. J. (1995). Nursing research in HIV/AIDS home care, Part 1: importance and methods. *Home Healthcare Nurse*, 13(3), 13-17.
- Janson-Bjerklie, S., Holzemer, W., & Henry, S.B. (1992). Patients perceptions of pulmonary problems and nursing interventions during hospitalisation for pneumocystis carinii pneumonia. *American Journal of Critical Care*, 1, 114-121.
- Joint United Nations Programme on HIV/AIDS World Health Organisation (2000). *AIDS Epidemic Update*. Author. [online.] Available: http://www.unaids.org/wac/2000/wad00/files/WAD_epidemic_report.htm
- Jones, P. D., Beaman, M. H., & Brew, B. J. (1997). HIV and opportunistic neurological infections. In G. Stewart (Ed.). *Managing HIV* (pp. 80-83). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Jones, P., & Loewenthal, M. (1994). Medical Management of HIV/AIDS and Antiviral Therapy. In J. Gold, R. Penny, M. Ross, S. Morey, G. Stewart, B. Donovan, & S. Berenger (Eds.). *The AIDS Manual* (3rd ed.), (pp 52-63). Sydney: Maclellann and Petty.
- Judd, F. K., & Mijch, A. M. (1994). Depression in patients with HIV and AIDS. *Australian and New Zealand Journal of Psychiatry*, 28(4), 642-650.

- Kaldor, J. M., McDonald, A. M., Blumer, C. E., Gertig, D. M., Patten, J. J., Roberts, M., Walker, C. C., Mullins, S. E., Bailey, K. A., & Chuah, C. P. (1993). The Acquired Immunodeficiency Syndrome in Australia: Incidence 1982-1991. *Medical Journal of Australia*, 158, 10-17.
- Kaldor, J., and Rubin, G. (1994). Epidemiology of HIV infection. In J. Gold, R. Penny, M. Ross, S. Morey, G. Stewart, B. Donovan, & S. Berenger (Eds.). *The AIDS Manual* (3rd ed.), (pp. 1-12). Sydney: MacLennan and Petty.
- Katz, M. H., Douglas J. M., Jr., Bolan, G. A., Marx, R., Sweat, M., Park, M. S., & Buchbinder, S. P. (1996). Depression and use of mental health services among HIV-infected men. *AIDS Care*, 8(4), 433- 442.
- Kelly, J. A., Murphy, D. A., Bahr, G. R., Koob, J. J., Morgan, M. G., Kalichman, S. C., Stevenson, L. Y., Brasfield, T. L., Bernstein, B. M., & St Lawrence, J. S. (1993). Factors associated with severity of depression and high risk sexual behaviour among persons diagnosed with Human Immunodeficiency Virus (HIV) infection. *Health Psychology*, 12(3), 215-219.
- Kelly, M. D., Lloyd, A. R., & Kemp, R. J. (1997). HIV, weight loss and wasting syndrome. In G. Stewart (Ed.). *Managing HIV* (pp. 113-114). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Kennedy, C. A., Skurnick, J. H., Foley, M., & Louria, D. B. (1995). Gender differences in HIV-related psychological distress in heterosexual couples. *AIDS Care*, 7(Suppl. 1), S33-S38.
- Kerlinger, F. M. (1986). *Foundations of Behavioural Research* (3rd ed.). New York: Wiley.
- Kermode, M. (1995). Patients' experiences of nursing interventions during hospitalisation with an AIDS-Defining Illness. *Australian Journal of Advanced Nursing*, 12(3), 20-30.
- Krause, R. M. (1993). Emerging patterns of heterosexual HIV infection and transmission. Closing statement. Conference Report. *International Journal of STD and AIDS*, 4, 348-352.
- Kuehnert, P. L. (1991). Community health nursing and the AIDS pandemic: case report of one community response. *Journal of Community Health Nursing*, 8(3), 137-146.
- Lander, S. M., & Reid, J. (1991). Toxoplasmosis: minimising the risk of pet-associated transmission in persons with HIV disease. *Home Healthcare Nurse*, 9(2), 33-35.
- Lang, C. (1993). HIV and quality of life: a rehabilitative perspective. *Health Visitor*, 66(12), 445-446.
- Langford, C. P. H., Bowsher, J., Maloney, J. P. B., & Lillis, P. (1997). Social Support: A Conceptual Analysis. *Journal of Advanced Nursing*, 25(1), 95-100.
- Law, M. G., McDonald, A. M., & Kaldor, J. M. (1996). Estimation of cumulative HIV incidence in Australia based on national case reporting. *Australian and New Zealand Journal of Public Health* 20, 215-217.
- Lawton, M. P. (1983). Environmental and other detriments of well-being in older adults. *Gerontologist*, 23, 349-357.
- Layzell, S., & McCarthy, M. (1992). Community-based health services for people with HIV/AIDS: a review from a health service perspective. *AIDS Care*, 4(2), 203-215.
- Layzell, S., & McCarthy, M. (1993). Specialist or generic community nursing care for HIV/AIDS patients? *Journal of Advanced Nursing*, 18(4), 531-537.
- Lempp, H., de Board, L., & Brown, J. (1994). A cycle of care: a model of community and hospital HIV/AIDS services. *British Journal of Nursing*, 3(22), 1198-1199; 1201-1204.

- Lewin, S.R., Crowe, S., Chambers, D.E., & Cooper, D.A. (1997). Antiretroviral Therapies for HIV(1997). Strategies of Care in Managing HIV. In G. Stewart (Ed.). *Managing HIV* (p 45-54). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Linn, J. G., Anema, M. G., Hodess, S., Sharpe, C., & Cain, V. A. (1996). Perceived health, HIV illness, and mental distress in African-American clients of AIDS counseling centers. *Journal of the Association of Nurses in AIDS Care*, 7(2), 43-51.
- Linn, J. G., Monning, R. L., Cain, V. A., & Usuh, D. (1993). Stage of illness, level of HIV symptoms, sense of coherence and physiological functioning in clients of community-based AIDS counselling centres. *Journal of the Association of Nurses in AIDS Care*, 4, 24-32.
- Lippmann, S. B., James, W. A., & Frier, R. L. (1993). AIDS and the family: implications for counselling. *AIDS Care*, 5(1), 71-78.
- Lo Biondo-Wood, G., & Haber, J. (1990). *Nursing Research* (3rd. Ed.). St Louis, USA: Mosby.
- Lubeck, D. P., Bennett, C. L., Mazonson, P. D., Fifer, S. K., & Fries, J. F. (1993). Quality of life and health service use among HIV-infected patients with chronic diarrhoea. *Journal of Acquired Immune Deficiency Syndromes*, 6(5), 478-484.
- Lubeck, D. P., & Fries, J. F. (1993). Health status among persons infected with immunodeficiency virus. A community-based study. *Medical Care*, 31, 269-276.
- Lucey, A., Bicknell, B. & Burke, D.; (1997). Retrospective review of referral forms from a HIV Unit to community nursing services, 1993-1995. Final *Program and Abstract Book of the 3rd International Conference of AIDS Impact – Biopsychosocial Aspects of HIV infection, Melbourne, Australia, June*.
- Lucey, A., Bicknell, B. & Burke, D.; (1998). A description of clients referred to community nurses from a HIV Unit in Sydney, 1993-1995. *Programme and Abstracts of the 10th Annual Conference of Australian Society for H.I.V Medicine, Newcastle, Australia, November*.
- Lucey, A., & Turbitt, P. (1992). Challenges in the management and maintenance of intrathecal AZT as a new therapy. *Published Abstracts and Indices of the 8th International Conference on AIDS/3rd STD World Congress, Amsterdam, The Netherlands, July*.
- Manfredi, R., Mastroianni, A., Coronado, O., & Chiodo, F. (1996). Therapeutic and diagnostic procedures in hospitalized AIDS patients with terminal illness. *AIDS Care*, 8(3), 373-376.
- Mann, J. M. (1993). Emerging patterns of heterosexual HIV infection and transmission. heterosexual transmission of HIV: A global view a decade later. *International Journal of STD & AIDS*, 4, 353-356.
- Marmot, M. (1999) The solid facts: The social determinants of health. *Health Promotion Journal of Australia*, 9(2), 133-139.
- Marriott, D. J. E., & McMurchie, M. (1997). HIV and advanced immune deficiency. In G. Stewart (Ed.). *Managing HIV*. (pp. 15-16). Sydney, Australia: Australasian Medical Publishing Company Limited.
- McCain, N. L., & Zeller, J. (1994). Research priorities for psychosocial aspects of nursing care in HIV disease. *Journal of the Association of Nurses in AIDS Care*, 5(2), 21-26.
- McCluskey, P. J., Hall, A. J., & Lightman, S. (1997). HIV and eye disease. In G. Stewart (Ed.). *Managing HIV* (pp 95-97). Sydney, Australia: Australasian Medical Publishing Company Limited.

- McCormick, W. C., Inui, T. S., Deyo, R. A., & Wood, R. W. (1991). Long-term care needs of hospitalised persons with AIDS: a prospective cohort study. *Journal of General Internal Medicine*, 6(1), 27-34.
- McMurray, A. (1991). Advocacy for community self-empowerment. *International Nursing Review* 39(1), 19-21.
- Meeks-Festa, L., McCarthy Uhle, S., Munjas, B., Gerszten, E., & Creger, A. (1994). HIV/AIDS Clients' satisfaction with selected aspects of clinic nursing services. *Journal of the Association of Nurses in AIDS Care*, 5(4), 37-44.
- Melbourne, K., Abbaticola, M., Rona, K., & Fisher, A. (1998). Tolerability and body composition of HIV infected individuals on retonavir-containing regimens. *Abstracts of the 38th ICAAC, San Diego, California, September*.
- Mierlak, D., Leon, A., & Perry, S. (1995). Does physical improvement reduce depressive symptoms in HIV-infected medical inpatients? *General Hospital Psychiatry*, 17(5), 380-384.
- Mijch, A. M., Clezy, K., and Furner, V. (1997). Women with HIV. In G. Stewart (Ed.). *Managing HIV* (pp. 128-130). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Millar, J. L., Goldstein, D., & Gelmon, K. A. (1997). HIV and Kaposi Sarcoma. In G. Stewart (Ed.). *Managing HIV* (pp. 103-106). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Miller, D., & Riccio, M. (1990). Non organic psychiatric and psychosocial syndromes associated with HIV-1 infection and disease. *AIDS*, 4, 381-388.
- Miller, R. F., Hingorami, A. D., & Foley, N. M. (1996). Pyrexia of undetermined origin in patients with Human Immunodeficiency Virus infection and AIDS. *International Journal of STD & AIDS*, 7, 170-175.
- Milliken, S.T., Clezy, K.R., Cooper, S.G., & Romeril, K.R. (1997). HIV-related lymphoma and other malignancies. In G. Stewart (Ed.). *Managing HIV* (pp. 13-14). Sydney, Australia: Australasian Medical Publishing Company Limited.
- MIMS Australia (1995). February/March. Med.Media Australia Pty. Ltd.
- Montaner, J. S. G., Le, T., Hogg, R., Ricketts, M., Sutherland, D., Strathdee, S. A., O'Shaughnessy, M., & Schechter, M. T. (1994). The changing spectrum of AIDS index diseases in Canada. *AIDS*, 8(5), 693-696.
- Moons, M., Kerkstra, A., and Biewenga, T. (1994). Specialised home care for patients with AIDS: an experiment in Rotterdam, The Netherlands. *Journal of Advanced Nursing*, 19(6), 1132-1140.
- Moore, C., & Appleby, S. (1993). HIV/AIDS caring for families in the community. *Health Visitor*, 66(12), 438-440.
- Naegle, M. A. (1994). Drug use and HIV: healthcare provider perspectives. *Journal of the Association of Nurses in AIDS Care*, 5(3), 39-46.
- National Centre in HIV Epidemiology and Clinical Research. (1993a). *Australian HIV Surveillance Report*, 9(3).
- National Centre in HIV Epidemiology and Clinical Research. (1993b). *Australian HIV Surveillance Report*, 9(4).
- National Centre in HIV Epidemiology and Clinical Research. (1994a). *Australian HIV Surveillance Report*, 10(2).

- National Centre in HIV Epidemiology and Clinical Research. (1994b). *Australian HIV Surveillance Report*, 10(4).
- National Centre in HIV Epidemiology and Clinical Research. (1995). *Australian HIV Surveillance Report*, 11(4).
- National Centre in HIV Epidemiology and Clinical Research. (2000a). *Australian HIV Surveillance Report*, 16(4).
- National Centre in HIV Epidemiology and Clinical Research. (2000b). *Annual Surveillance Report 2000. The University of New South Wales. Sydney NSW.*
- National Centre in HIV Epidemiology and Clinical Research. (2001). *Australian HIV Surveillance Report*, 17(1).
- National Health Strategy. (1992). *Enough to make you sick: How income and environment affect health* (Research Paper No. 1). Canberra, Australian Capital Territory: Author.
- Nazarko, L. (1998). Improving discharge: the role of the discharge coordinator. *Nursing Standard*, 12(49), 35-37.
- Newshan, G. T., & Wainapel, S. F. (1993). Pain characteristics and their management in persons with AIDS. *Journal of the Association of Nurses in AIDS Care*, 4(2), 53-59.
- Nichols, S. (1985) Psychosocial reactions of persons with the Acquired Immunodeficiency Syndrome. *Annals of Internal Medicine*, 103, 765-767.
- Nokes, K., Wheeler, K., & Kendrew, J. (1994). Development of an HIV Assessment tool. *Image: The Journal of Nursing Scholarship*, 26, 133-138.
- Norbeck, J. S. (1988) Social Support. In J. J. Fiitzpatrick, R. L. Taunton, & J. Q. Benoliel, (Eds.). *Annual Review of Nursing Research*. New York: Springer,.
- Norvsi, M. J. (1997) *Guide to Data Analysis*. New Jersey: Prentice Hall.
- NSW Department of Health.(1995). *Guidelines and Competencies for the Handling of Cytotoxic Drugs and Related Waste in NSW Health Care Establishments*. (Circular No. 95/49 File no. A12291) [online]. Available: <http://www.health.nsw.gov.au/fcsd/rmc/cib/circulars/1995/cir95-49.pdf> (1995, Jun. 30).
- NSW Department of Health. (1995). *Draft Interim Minimum Data Set for Palliative Care*. Sydney, New South Wales: Author.
- NSW Public Health Act (1991) no. 10. Reprinted 5 July, 1993.
- NSW Workcover Authority (1995). *Guidelines for handling cytotoxic drugs and related waste in health care establishments*. (2nd Ed.). Sydney, New South Wales: Author.
- O'Dowd, M. A. (1995). Psychosocial issues in the care of people living with HIV/AIDS. *International AIDS Society*, 3, 10-13.
- O'Neill, W. M., & Sherrard, J. S. (1993). Pain in Human Immunodeficiency Virus disease: a review. *Pain*, 54(1), 3-14.
- Ostrow, D. G., VanRaden, M. J., Fox, R., Kingsley, L. A., Dudley, J., Kaslow, R. A., & the Multicenter AIDS Cohort Study. (1990). Recreational drug use and sexual behaviour change in a cohort of homosexual men. *AIDS*, 4(8), 759-765.
- Ownby, K. (1995). Management of the haematological manifestations of HIV and AIDS. *Journal of the Association of Nurses in AIDS Care*, 6(4), 9-15.
- Palmer, G., & Short, S. (1989). Organising health care services. *Health Care and Public Policy* (pp. 78-119). Melbourne: Macmillan Education Australia.

- Penfold, J., & Clark, A. J. (1992). Pain syndromes in HIV infection. *Canadian Journal of Anaesthesia*, 39(7), 724-730.
- Perkins, D. O., Davidson, E. J., Leserman, J., Liao, D., & Evans, D. L. (1993). Personality disorder in patients infected with HIV: a controlled study with implications for clinical care. *American Journal of Psychiatry*, 150(2), 309-315.
- Pethebridge, A. M., & Plummer, D. C. (1997). Men and HIV. In G. Stewart (Ed.). *Managing HIV* (pp. 125-126). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Petrou, S., Dooley, M., Whitaker, L., Beck, E., Kupek, E., Wadsworth, J., Miller, D., & Renton, A. (1996). Community service needs of people with HIV infection in London. *AIDS Care*, 8(4), 467-478.
- Phillips, A. N., Antunes, F., Stergious, G., Ranki, A., Jensen, G. F., Bentwich, Z., Sacks, T., Pedersen, C., Lundgren, J. D., and Johnson, A. M., for the AIDS in Europe Study Group. (1994) A sex comparison of rates of new AIDS-defining disease and death in 2,554 AIDS cases. *AIDS*, 8(6), 831-835.
- Plummer, D. C., & Furner, V. (1997). HIV and sexually transmitted diseases. In G. Stewart (Ed.). *Managing HIV* (pp. 115-118). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Pritchard-Jones, J. (1999). *Hepatitis C Manual for General Practitioners and Other Health Care Workers*. Central and South Eastern Sydney Area Health Services.
- Radloff, L. S. (1977) The CES-D Scale: A self report depression scale for research in the general population. *Applied Psychology Measurement*, 1, 385-401.
- Reedy, L., & Bragg, R. (2000). *Earlier Discharge Issues Paper*. The Community Health Collaboration, Council of Social Service of NSW.
- Reilly, C. A., Holzemer, W. L., Henry, S. B., Slaughter, R., & Portillo, C. (1997). A comparison of patient and nursing ratings of human immunodeficiency virus related signs and symptoms. *Nursing Research*, 46 (6), 318-323.
- Research Institute for Consumer Affairs and Disabilities Study Unit (1990). *Caring for Someone with AIDS*. Consumers Association, London.
- Ropka, M. (1994). Symptom management. In W. L. Holzemer, & C. J. Portillo, (Eds.). *Proceedings of the American Academy of Nursing HIV/AIDS Nursing Care Summit* (p 137). Washington: American Academy of Nursing.
- Rorden, J. W., & McLennan, J. (1992). *Community Health Nursing: Theory and Practice*, (pp 325-331). Sydney: Harcourt Brace Jovanovich.
- Rose, M. A. (1993). Health concerns of women with HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 4(3), 39-45.
- Rose, M. A., & Clark-Alexander, B. (1996). Quality of life and coping styles of HIV-positive women with children. *Journal of the Association of Nurses in AIDS Care*, 7(2), 28-34.
- Ross, M. W. (1997). How psychosocial aspects of HIV infection can affect health: Strategies of care in managing HIV. In G. Stewart (Ed.). *Managing HIV* (pp. 42-44). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Ross, M. W., Hunter, C. E., Condon, J., Collins, P., & Begley, K. (1994). The Mental Adjustment to HIV Scale: measurement and dimensions of response to AIDS/HIV disease. *AIDS Care*, 7(4), 407-411.

- Saag, M.S., Holodniy, M., Kuritzkes, D.R., O'Brien, W.A., Coombs, R., Poscher, M.E., Jacobsen, D.M., Shaw, G.M., Richman, D.D., & Volberding, P.A. (1996). HIV Viral Load Markers in Clinical Practice. *Nature Medicine*, 2(6), 625-629.
- Salsberry, P. J., Nickel, J. T., & O'Connell, M. (1991). AIDS research in the community: a case study in collaboration between researchers and clinicians. *Public Health Nursing*, 8(3), 201-207.
- Salzer, J., Waters, H., & Yow, P. (1987). AIDS: holistic home care. *Home Healthcare Nurse*, 5(2), 10-21.
- Scalon, K. (1991). *"Anyway, it's Just a Pamphlet."* Unpublished master's thesis, University of Sydney, Sydney, New South Wales, Australia.
- Scheier, M. F., & Bridges, M. W. (1995). Person variables and health: personality predispositions and acute psychological states as shared determinants for disease. *Psychosomatic Medicine*, 57(3), 255-268.
- Schietinger, H. (1986). AIDS beyond the hospital. 1. A home care plan for AIDS. *American Journal of Nursing*, 86(9), 1021-1028.
- Schmidt, J. (1992). Case management problems and home care. *Journal of the Association of Nurses in AIDS Care*, 3(3), 37-44.
- Schroeder, C. (1993). Nursing's response to the crisis of access, costs, and quality in health care. *Advances in Nursing Science*, 16(1), 1-20.
- Scott, M., & Irvine, S. S. (1997). What do people with HIV, their carers and families want of their medical carers? In G. Stewart (Ed.). *Managing HIV* (pp. 156-157). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Sharp, J. W., Coleman, E., Starling, N., Cline, J., & Rehm, S. J. (1991). Hospital utilization for AIDS: are all hospital days necessary? *Quality Review Bulletin*, 17(4), 113-119.
- Sherr, L., Hedge, B., Steinhart, K., Davey, T., & Petrack, J. (1992). Unique patterns of bereavement in HIV: implications for counselling. *Genitourinary Medicine*, 68(6), 378-381.
- Sievert, W., Shaw, D.R., & Edwards, P. (1997). HIV, gastrointestinal and hepatobiliary disease. In G. Stewart (Ed.). *Managing HIV* (pp. 70-75). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Singer, E.J., Zorilla, C., Fahy-Chandon, B., Chi, S., Syndulko, K., & Tourtellotte, W.W. (1993). Painful Symptoms Reported by Ambulatory HIV-Infected Men in a Longitudinal Study. *Pain*, 54(1), 15-19.
- Skodal Wilson, H. (1989). *Research in Nursing* (2nd Ed.). California: Addison-Wesley Publishing Company.
- Slone, M., & Stephany, T. (1995). Stresses of hospice home care nurses caring for AIDS patients: a pilot study. *The American Journal of Hospice and Palliative Care*, 1995, (January/February), 32-36.
- Smith, A. I., & Pigott, P. C. (1997). HIV and respiratory disease. In G. Stewart (Ed.). *Managing HIV* (pp. 87-90). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Smith, A. R. (1991). Examination of nursing diagnoses for adults hospitalized with Acquired Immunodeficiency Syndrome. *Nursing Diagnosis*, 2(3), 111-118.
- Smith, M.Y., & Rapkin, B. D. (1995). Unmet needs for help among persons with AIDS. *AIDS Care* 7, 353-363.
- Snee, T. (1994). Challenges old and new. *Nursing Standard*, 9(5), 49-50.

- Sousa, K. H., Holzemer, W. L., Henry, S. B., & Slaughter, R. (1999). Dimensions of health-related quality of life persons living with HIV disease. *Journal of Advanced Nursing*, 29(1), 178-187.
- Sowell, R. L. (1995). Community-based HIV case management: challenges and opportunities. *Journal of the Association of Nurses in AIDS Care*, 6(2), 33-40.
- Spence Laschinger, H. K., Goldenberg, D., & Dal Bello, D. (1995) Community Health Nurses' HIV care behaviour. *Journal of Community Health Nursing*, 12(3), 147-159.
- Stanley, S. (1994). HIV nursing: caring for the future. *Journal of the Association of Nurses in AIDS Care*, 5(2), 29-30.
- Stewart, G. (1994). Immunology. In J. Gold, R. Penny, M. Ross, S. Morey, G. Stewart, B. Donovan, & S. Berenger (Eds.). *The AIDS Manual* (3rd ed.), (pp 18-27.) Sydney: MacLennan and Petty.
- Stewart, G. J. (1997). HIV-discordant couples. In G. Stewart (Ed.). *Managing HIV* (p. 127). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Stewart, G. J., Irvine, S. S., Scott, M., Kelleher, A. D., Marriott, D. J. E., McKnight, I., Pethebridge, A. M., Wodak, A., & Zeigler, J. (1997). Strategies of care in managing HIV. In G. Stewart (Ed.). *Managing HIV* (pp. 3-8). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Stewart, M. J. (1993). *Integrating Social Support In Nursing*. Newbury Park, CA.: Sage.
- Stowe, A., Ross, M. W., Wodak, A., Thomas, G. V., & Larson, S. A. (1993). Significant relationships and social supports of injecting drug users and their implications for HIV/AIDS services. *AIDS Care*, 5(1), 23-33.
- Street, A. M., & Gibson, J. (1997). HIV and haematological disease. In G. Stewart (Ed.). *Managing HIV* (pp. 98-99). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Summerbell, C. D., Perrett, J. P., & Gazzard, B. G. (1993). Causes of weight loss in Human Immunodeficiency Virus infection. *International Journal of STD & AIDS*, 4, 234-236.
- Sutherland, D. (1994). Laboratory Assessment. In J. Gold, R. Penny, M. Ross, S. Morey, G. Stewart, B. Donovan, & S. Berenger (Eds.). *The AIDS Manual* (3rd ed.), (pp 44-51) Sydney: MacLennan and Petty.
- Swan, J. H., Benjamin, A. E., & Brown, A. (1992). Skilled nursing facility care for persons with AIDS: comparisons with other patients. *American Journal of Public Health*, 82(3), 453-455.
- Thompson, S. C., Nanni, C., & Levine, A. (1996). The stressors and stress of being HIV-positive. *AIDS Care*, 8(1), 5-14.
- Turjanica, M. A., Ardabell, T. R., Schiffer, N. A., Poirier, M., & Brodeur, S. (1994). A multidisciplinary, multifaceted HIV program: linking the resources. *Nursing Administration Quarterly*, 18(2), 41-45.
- Twyman, D. M., & Libbus, M. K. (1994). Case-management of AIDS clients as a predictor of total inpatient hospital days. *Public Health Nursing*, 11(6), 406-411.
- UNAIDS / WHO (1999). Global AIDS statistics. *AIDS*, 11(5), 622.
- Ungvarski, P. J. (1992). Nursing care of adults with HIV/AIDS. *Home Healthcare Nurse*, 10(5), 68.
- Ungvarski, P. (1994). Comorbidities of HIV-1/AIDS in adults. *Journal of the Association of Nurses in AIDS Care*, 5(6), 35-44.

- Ungvarski, P. J., & Hurley, P. M. (1995). Nursing research in HIV/AIDS home care, Part 2: results and implications. *Home Healthcare Nurse*, 13(4), 9-13.
- Ungvarski, P. J., Scimmdt, J., and Neville, S. (1994). Planning home care services of people living with AIDS. *Home Healthcare Nurse*, 12(2), 17-23.
- Valente, S., Saunders, J. M., & Umangb (1993). Self care, psychological distress and HIV disease. *Journal of the Association of Nurses in AIDS care*, 4, 15-25.
- Valente, S. M., & Saunders, J. M. (1994). Management of suicidal patients with HIV disease. *Journal of the Association of Nurses in AIDS Care*, 5(6), 19-29.
- Venning, M. (1990). Helping people to die at home. *Australian Nurses Journal*, 20(2), 17-19.
- Visintini, R., Bagnato, E., Campanini, S., Fontana, A., Novella, L., & Maffei, C. (1995). An assessment of self-Esteem in HIV-positive patients. *AIDS Care*, 7(Suppl. 1), S99-S104.
- Wang, S.A., Panlilio, A. L., & The HIV PEP Registry Group. (1998). Experience of Health Care Workers taking PEP after occupational human immunodeficiency virus exposures. Findings of the HIV PEP Registry. *Abstracts of the 38th ICAAC, San Diego, California, September*.
- Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C., & Robertson, B. (1988). Development of a questionnaire measure of adjustment to cancer: The MAC Scale. *Psychological Medicine*, 18, 203-209.
- Whyte, B. M., & Cooper, D. A (1988). The surveillance definition of the Acquired Immunodeficiency Syndrome and the Clinical Classification of Infection with the Human Immunodeficiency Virus Type 1. *Medical Journal of Australia*, 149, 368-373.
- Widman, M., Light, D. W., and Platt, J. J. (1994). Barriers to out of hospital care for AIDS patients. *AIDS Care*, 6(1), 59-67.
- Wodak, A., & van Beek, I. (1997). HIV and injecting drug use. In G. Stewart (Ed.). *Managing HIV* (pp. 142-143). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Wong, D., & Shumack, S. (1997). HIV and skin disease. In G. Stewart (Ed.). *Managing HIV* (pp. 62-66). Sydney, Australia: Australasian Medical Publishing Company Limited.
- World Health Organisation (1974). *Basic Documents*. (36th Ed.). Geneva: Author.
- World Health Organisation. (1986) *Ottawa Charter for Health Promotion*, Ottawa: Author.
- World Health Organisation. (1993). *Global AIDS Statistics Weekly Epidemiological Record*, 68(2), 193-196.
- World Health Organisation (1995) *Global AIDS Statistics Weekly Epidemiological Record*, 70(2), 193-200.
- World Health Organisation (1998). *The solid facts: Social determinants of health*. In R. Wilkinson & M. Marmot (Eds.). International Centre Health and Society.
- World Health Organisation (1999). Global AIDS Statistics. *Weekly Epidemiological Record*, 48(3), 401-404.
- Wright, E. J., Brew, B. J., Currie, J. N., & McArthur, J. C. (1997). HIV-induced neurological disease. In G. Stewart (Ed.). *Managing HIV* (pp. 76-79). Sydney, Australia: Australasian Medical Publishing Company Limited.
- Wright, J., Henry, S. B., Holzemer, W. L., & Falknor, P. (1993). Evaluation of community-based nurse case management activities for symptomatic HIV/AIDS clients. *Journal of the Association of Nurses in AIDS Care*, 4(2), 37-47.

REFERENCES

- Zeller, J. M., Swanson, B., & Cohen, F. L. (1993). Suggestions for clinical nursing research: symptom management in AIDS patients. *Journal of the Association of Nurses in AIDS Care*, 4(3), 13-17.

APPENDIX A

ANCA

Australian National Council on AIDS

06 JUN 1994

BULLETIN

No 18

DEFINITION OF HIV INFECTION AND AIDS-DEFINING ILLNESSES

The Intergovernmental Committee on AIDS (IGCA), representing the Commonwealth and all Australian State and Territory Health Departments, in consultation with the National Centre for HIV Epidemiology and Clinical Research (NCHECR) and the Communicable Diseases Network-Australia/New Zealand, has agreed to modify the AIDS case definition in Australia by the addition of the following three clinical conditions:

pulmonary tuberculosis;
recurrent pneumonia; and
invasive cervical cancer.

The new definition is effective in Australia from 1 January 1993.

The complete Australian HIV definition and AIDS defining illnesses definitions are listed below.

DEFINITION OF HIV INFECTION

- (i) Repeatedly reactive screening tests for HIV antibody, confirmed by the use of supplementary tests*;

or

- (ii) direct identification of HIV by virus isolation.

*Supplementary (or confirmatory) test: a test with higher specificity for detection of HIV antibody than screening (or first line) tests.

DEFINITION OF AIDS-DEFINING ILLNESSES

Candidiasis of the bronchi, trachea or lungs - definitive diagnosis only

Gross inspection by endoscopy or autopsy or by microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface), not from a culture.

Oesophageal candidiasis - definitive or presumptive diagnosis

Definitive diagnosis: as for candidiasis of the bronchi, trachea or lungs. Presumptive diagnosis:

- (i) recent onset of retrosternal pain on swallowing; and
- (ii) oral candidiasis diagnosed by the gross appearance of white patches or plaques on an erythematous base or by the microscopic appearance of fungal mycelial filaments in an uncultured specimen scraped from the oral mucosa.

Invasive cervical cancer - definitive diagnosis only

Histological evidence of cancer.

Coccidioidomycosis, disseminated or extrapulmonary - definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cryptococcosis, extrapulmonary - definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cryptosporidiosis, of more than one month's duration - definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cytomegalovirus disease, other than liver, spleen or lymph nodes - definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cytomegalovirus retinitis, with loss of vision - definitive or presumptive diagnosis

Definitive diagnosis: as for cytomegalovirus disease, other than liver, spleen or lymph nodes.

Presumptive diagnosis: A characteristic appearance on serial ophthalmoscopic examinations, for example discrete patches of retinal whitening with distinct borders, spreading in a centrifugal manner along the paths of blood vessels, progressing over several months, and frequently associated with retinal vasculitis, haemorrhage, and necrosis. Resolution of active disease leaves retinal scarring and atrophy with retinal pigment epithelial mottling.

Encephalopathy, HIV related - definitive diagnosis only

Clinical findings of disabling cognitive or motor dysfunction interfering with occupation or activities of daily living, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection that could explain the findings. Methods to rule out such concurrent illness and conditions must include cerebrospinal fluid examination and either brain imaging (computed tomography or magnetic resonance) or autopsy.

Herpes simplex: chronic ulcer(s) of more than one month's duration, bronchitis, pneumonitis or oesophagitis - definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Histoplasmosis, disseminated or extrapulmonary - definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Isosporiasis, chronic intestinal, of more than one month's duration - definitive diagnosis only

Microscopy (histology or cytology).

Kaposi's sarcoma - definitive or presumptive diagnosis

Definitive diagnosis: Microscopy (histology or cytology).

Presumptive diagnosis: A characteristic gross appearance of an erythematous or violaceous plaque-like lesion on skin or mucous membrane. Note: Presumptive diagnosis of Kaposi's sarcoma should not be made by clinicians who have seen few cases of it.

Lymphoma, Burkitt's - definitive diagnosis only

Microscopy (histology or cytology).

Lymphoma, immunoblastic - definitive diagnosis only

Microscopy (histology or cytology).

Lymphoma, primary, of brain - definitive diagnosis only

Microscopy (histology or cytology).

***Mycobacterium tuberculosis* complex, any site, pulmonary or extrapulmonary - definitive or presumptive diagnosis**

Definitive diagnosis: Isolation (or culture if preferred terminology) of *Mycobacterium tuberculosis*, *Mycobacterium bovis* or *Mycobacterium africanum* from a clinical specimen.

Presumptive Diagnosis: Demonstration of acid-fast bacilli in a clinical specimen or in a histopathological lesion when a culture is not available, in a person with signs or symptoms compatible with tuberculosis; or evidence of resolution of disease where treatment with two or more antituberculosis medications have been prescribed and follow-up has been instigated.

Non-tuberculous mycobacterial disease, disseminated or extrapulmonary - definitive or presumptive diagnosis

Definitive diagnosis: Culture

Presumptive diagnosis: Microscopy of a specimen from normally sterile body fluids, or tissue from a site other than lungs, skin or cervical or hilar lymph nodes that shows acid-fast bacilli of a species not identified by culture, in a person with signs, symptoms or immunological profile compatible with disseminated disease.

***Pneumocystis carinii* pneumonia - definitive or presumptive diagnosis**

Definitive diagnosis: Microscopy (histology).

Presumptive diagnosis:

- (i) a history of dyspnoea on exertion or non-productive cough of recent onset (within the past three months); and
- (ii) chest x-ray evidence of diffuse bilateral interstitial infiltrates or evidence by gallium scan of diffuse bilateral pulmonary disease; and
- (iii) arterial blood gas analysis showing an arterial pO₂ of <70mm Hg or a low respiratory diffusing capacity (<80% of predicted values) or an increase in the alveolar-arterial oxygen tension gradient; and
- (iv) no evidence of a bacterial pneumonia.

Pneumonia, recurrent bacterial - definitive or presumptive

Definitive diagnosis: Two or more episodes occurring within a 12 month interval, of acute (new x-ray evidence, not present earlier) pneumonia. Both episodes must have culture (or other organism specific diagnostic method) proven infection with a pathogen that typically causes pneumonia (other than *Pneumocystis carinii* or *Mycobacterium tuberculosis*) and radiological evidence of pneumonia.

Presumptive diagnosis: Two or more episodes occurring within a 12 month interval of acute (new symptoms, signs or x-ray evidence not present earlier) pneumonia, based on clinical or radiological evidence.

Progressive multifocal leukoencephalopathy - definitive diagnosis only

Microscopy (histology or cytology)

***Salmonella* septicemia, recurrent - definitive diagnosis only**

Culture proven infection with *Salmonella* species.

Toxoplasmosis - definitive or presumptive diagnosis

Definitive diagnosis: Microscopy (histology or cytology).

Presumptive diagnosis: Toxoplasmosis of brain

- (i) recent onset of a focal neurological abnormality consistent with intracranial disease or a reduced level of consciousness; and

evidence by brain imaging (computed tomography or nuclear magnetic resonance) of a lesion having a mass effect or the radiographical appearance of which is enhanced by injection of contrast medium; and

serum antibody to toxoplasmosis or successful response to therapy for toxoplasmosis.

Wasting syndrome due to HIV infection - definitive diagnosis only

Findings of profound involuntary weight loss of >10% of baseline body weight plus either chronic diarrhoea (at least two loose stools per day for ≥ 30 days), or chronic weakness and documented fever (for ≥ 30 days, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that could explain the findings (for example cancer, tuberculosis, cryptosporidiosis or other specific enteritis).

Bacterial infection affecting a child less than 13 years of age - definitive diagnosis only

Laboratory diagnosis of multiple or recurrent bacterial infection (any combination of at least two within a 2-year period) of the following types: septicaemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity (excluding otitis media or superficial skin or mucosal abscesses), caused by *Haemophilus*, *Streptococcus* (including *Pneumococcus*) or other pyogenic bacteria.

Lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia affecting a child less than 13 years of age - definitive or presumptive diagnosis

Definitive diagnosis: Microscopy (histology or cytology).

Presumptive diagnosis: Lymphoid interstitial pneumonia - bilateral reticulonodular interstitial pulmonary infiltrates present on chest x-ray for two months or more, with no pathogen identified and no response to antibiotic treatment. Other causes of interstitial infiltrates should be excluded, such as tuberculosis, *Pneumocystis carinii* pneumonia, cytomegalovirus infection or other viral or parasitic infections.

References:

Centers for Disease Control and Prevention. 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *MMWR* 1992;41(No RR-17):1-19.

Whyte BM and Cooper DA. The surveillance definition of the acquired immunodeficiency syndrome and the clinical classification of infection with the human immunodeficiency virus type 1. *Med J Aust* 1988;149:368-373.

For further copies of this bulletin please contact the Secretariat, Australian National Council on AIDS, GPO Box 9848, Canberra ACT 2601, telephone 06/289 7767.

April 1994

APPENDIX B

The Prince Henry, The Prince of Wales and The Prince of Wales Children's Hospitals
Facilities of the Eastern Sydney Area Health Service

COMMUNITY NURSING REFERRAL

Surname		Medical Record Number
Other Names		Date of birth
Classification	Sex	Admission Date

(affix label)

Date:

Referred to:

Previous Contact: Yes/ No/ Unsure

Address:

Phone: Facility: PHH ☐ POWH ☐ POWCH ☐ Discharge Date:

Weight:Kg Social Status: M D'f Sep S W D

Pension: Yes/No No.: Nationality: Language: ...

Contact Person: Relationship:

Address: Phone:

Local Doctor: Phone:

Allergy:

Diagnoses:

Operative Procedures: ...

To be filed in Medical Record

COMMUNITY NURSING REFERRAL

Condition on Discharge:

Mobility:

A.D.L.:

Medications:

Mental State:

Discharge Follow Up: V.M.P. [] L.M.O. [] Community Nurse [] Occupational Therapy [] Support Care Team []

Social Work [] Physiotherapy [] O.P.D. [] Home Help [] Meals On Wheels [] Other (please specify)

Appointments or Arrangements made for Follow Up: Yes/No/Not Applicable

Signature:
Community Liaison Nurse

APPENDIX C

CODE: /

b1)Date of Referral: NK/NS

a)Date of Admission: NK/NS b)Date of Discharge: NK/NS

c)Year of HIV Diagnosis: d)Last CD4 Count: e)Weight:

1)..... 2)..... 3)..... 4)..... 5)..... 6).....
8)..... 9)..... 10)..... 11)..... 12).....

g) Past Other Diagnoses: 1)..... 2)..... 3)..... 4)..... 5)..... 6).....
7)..... 8)..... 9)..... 10)..... 11)..... 12).....

h) Allergies: *c* 1)..... 2)..... 3).
4)..... 5)..... 6).....

i) Past Surgery: 1)..... 2)..... 3).....
..... 5)..... 6).....

j)Symptoms/Signs During Admission:

1)..... 2)..... 3)..... 4)..... 5)..... 6).....
8)..... 9).....10).....11).....12).....
13).....14).....15).....16).....17).....18).....

k) Cause/Site of Pain: 1)..... 2)..... 3)..... 4)..... 5)..... 6).....

1)Psycho/Emotional Status:c 1)..... 2)..... 3)..... 4)..... 5)..... 6).....
8)..... 9).....10).....11).....12)....

m)New Diagnoses/Reasons For Admission: 1)..... 2)..... 3)..... 4)..... 5)..... 6).....
7)..... 8)..... 9).....10).....11).....12).....

n) Highlighted Ongoing Issues on Discharge: c NK/NS 1)..... 2)..... 3)..... 4)..... 5)..... 6).....

o/Treatments on Discharge:		Self	Carer	G.C.N.	Clinic	G.P.
No. of oral meds:	Y/N					
Subcut meds:	Y/N					
I.V. meds:	Y/N					
Ganciclovir	Y/N					
Foscarnet	Y/N					
Amphotericin	Y/N					

Other antibiotic Y/N
 I.M.I. meds: Y/N
 No. of topical meds: Y/N
 N/G / Enteral feeds:Y/N
 Per rectum: Y/N.....
 Nebulised: Y/N.....
 Puffer: Y/N.....
 Aural: Y/N.....
 Dressings: Y/N
 Eye: Y/N
 Physio: Y/N.....
 Other: Y/N

p)Date of Death: NK

SECTION 2

a)C.H.C. Referred to: Area of Referral:c

State Other:

b)No. of Referrals so far to this Community Nursing Team:

c)New Client to this Community Nursing Team: Y/N

d)Specific Requests made to G.C.N.s: Y/N

Monitor symptoms:	Emotional support:	Home assessment:
Fill dossette box:	Give subcut meds:	Give I.V. meds:
Provide equipment:	Encourage Med F/U:.....	Monitor diet. intake:
Pain control:	Chest physio:	Liaise with MO,HCW:
Give IMI/SC meds:	Increase supports:	Palliation/Terminal C:
Assistance ADLs	Dressing(s):	Pressure area care:
Co-ordinate serv.	Encour. autonomy:	Mouth care:

Other 1: Other 2:

Other 3: Other 4:

Support client/carer to:

Fill dossette box:	Give IMI/SC meds:	Give NG Ent.feed:
Chest physio:	Give oral meds:	Assistance ADLs:
Dressing(s)	Pressure area care:	Mouth care:
Palliat/TermC:	Give I.V. meds:	Encour. autonomy:

Other 1: Other 2:....

Other 3: Other 4:

e)Mobility:

Not stated Immobile Ambulant Wheelchair As Tolerated/Able

Independent/Assistance With aid/Without aid/Not stated if aid used Other

f)Personal Care: Other
Not stated Independent Dependent Supervision Assistance As Able/Tolerated

g)Home Duties: Other
Not stated Independent Dependent Supervision Assistance As Able/Tolerated

h)Contact Details of Ward Based S/W Stated on Referral: Y/N

SECTION 3

a)D.O.B: NK NS **b)Nationality:** NK NS *c*

c)Language: NK NS *c*

d)Sex:*c* **e)Res. Postcode:** **f)Pension:**Y/N/NK/NS

g)Living Alone: Y/N/NK/NS **h)Sexuality:** HET/HOM/BI/HOM or BI/HET or BI/
NK/NS

i)Phone: Y/N/NK/NS

j)Living With:*c* **k)Contact Person Relationship:***c*

l)Stated 'Friend' has also been Referred to as (same sex) Partner Y/N/NA

m)Orientated: Y/N/NK/NS

n)Past Unprescribed Substance Use:*c*

1. 2. 3. 4. 5. 6. 7. 8.

o)Recent Unprescribed Substance Use:*c*

1. 2. 3. 4. 5. 6. 7. 8.

p)Current Cigarette Smoker: Y/N/NS/NK **q) Current alcohol:** nil/social/NS/NK/
Y

r)Other Community Services Accepted:

NK NS Physio Home Care M.O.W C.S.N Ankali Transport

O.T S.W Local G.P B.G.F. A.O.D Services Hydrotherapy

Support Groups Dietitian Enteral Nutrition Service Counsellor

Other 1: Other 2: Other 3:

s)Client Given Name(s) of Local G.Ps: Y/N/NK/NS

t)Social Worker Help:NK NS Financial Accommodation Emotional

Community Support Referral/Info Relaxation Techniques Counselling

Visitor Support Other 1: 2: 3:

u)Specific Comment 1:

Specific Comment 2:

Specific Comment 3:

Specific Comment 4:

Specific Comment 5:

Specific Comment 6:

Specific Comment 7:

Specific Comment 8:

Specific Comment 9:

Specific Comment 10:

Specific Comment 11:

v)Researcher Comment 1:

Researcher Comment 2:

Reaearcher Comment 3:

Researcher Comment 4:

Researcher Comment 5:

Reaearcher Comment 6:

APPENDIX D

DATA COLLECTION FORM GUIDE (3)

Code: Client No. (see patient code form)/No. of this referral for this client

SECTION 1

a) d/m/y or NS

b) d/m/y or NS

b) d/m/y or NS

c) state year, NK or NS

d) state count, NK or NS

e) kg, NK or NS

f) Use reference codes or circle NK/NS

g) create code

A nil known... B nil stated... C ^{eg pulmonary, pelvic} internal abscess ^{prostatic, hepatic} alleged assault
 drug toxicity/intolerance... F anaemia... G appendicitis... H ^{arthropathy} arthritis...
 E allergic reaction... I asthma... J ^{atypical/bacterial} pneumonia... K ^{bipolar} disorder... L cellulitis...
 M depression... N ^{seborrhoeic} dermatitis... O ^{otitis media/externa} ear disorder... P endocarditis...
 Q ^{perianal abscess} fall/injury... R fissure in ano ^{haemorrhoids}... T hepatitis A, B, C...
 U ^{herpes simplex} virus... V ^{human papilloma} virus... W ^{insertion/repair} joint effusion... X ^{review/removal long} term venous access device...
 Y ^{new H.I.V. antibody} diagnosis... Z ^{pancytopenia}... AA ^{Renal failure/} dysfunction... AB ^{sclerosing} cholangitis...
 AC ^{sebaceous} cyst... AD ^{respite}... AE ^{septic} septicaemia... AF ^{arthritides} arthritis...
 AG sinusitis... AH ^{Sjogrens} syndrome... AI ^{psoriasis} skin rash... AJ ^{superior vena cava} obstruction...
 AK tendonitis... AL ^{fungal skin infection/} tinea... AM ^{transverse} myelitis... AN ^{chemotherapy} internal ulcers...
 AO ^{naso gastric/} central feed... AP ^{cerebral} atrophy... AQ ^{branchectasis}... AR ^{I.V. therapy} I.V. therapy...
 AS ^{epididymo} palliation... AT ^{duodenitis} orchitis... AU gastritis... AV pancreatitis...
 AW ^{back pain} desensitisation... AX tuberculosis... AY syphilis... AZ head injury...

cerebral	intravenous	oral/dental
BA infarct.....	BB line infection.....	BC oesophagitis.....
BD disease.....	BE skin abscess/lesion.....	BF cardiomyopathy Ischaemic Heart Disease, Cardiac myocardiitis.....
BG failure/dysfunction.....	BH surgery.....	
hiatus/inguinal	sinus	venous
BI hernia.....	BJ formation.....	BK thrombosis.....
BL thrombophlebitis.....		
social	spina	gynaecological
BM problems.....	BN diabetes.....	BO brida.....
BP symptoms.....		
vaginal	urinary tract	pelvic inflammatory
BQ thrush.....	BR infection.....	BS disease.....
BT gonorrhoea.....		
herpes	alcohol/other drug	HIV
BU zoster.....	BV with ocular.....	BW retinopathy.....
BX giardia.....		
retinal	cholelithiasis	
BY detachment.....	cholecystitis	
BZ in gall bladder.....	CA hydrocephalus.....	CB bursitis.....
		squamous cell
C cheiria.....	CD visual defect.....	CE hypothyroidism.....
CF carcinoma.....		enlarged prostate
CG ulcer.....	CH conjunctivitis.....	CI prostatism.....
CJ schizophrenia.....		
liver	basal cell	metabolic
CK disease.....	CL carcinoma.....	CM acidosis.....
CN psychosis.....		
grand/petit mal seizure(s)		deep venous
CO epilepsy.....	CP hypertension.....	CQ thrombosis.....
CR pancreatitis.....		glandular
pulmonary		Reiter's
CS embolus.....	CT pneumothorax.....	CU fever.....
CV syndrome.....		
seizures		
CW rhabdomyolysis.....	CX epilepsy.....	CY campylobacter.....
CZ osteoporosis.....		
antisocial traits/	conversion	anxiety disorder/
DA adenovirus.....	DB personality.....	DC disorder.....
DD attack(s).....		
addisons		cancer/
DE poly p.....	DF migraine.....	DG disease.....
DH malignancy.....		
cushings	testicular	diverticular
DI syndrome.....	DJ torsion.....	DK disease.....
DL bells palsy.....		
pyomyositis	post partum	idiopathic pre H.I.V.
DM myositis.....	DN haemorrhage.....	DO thrombocytopenia.....
DP attack.....		
cerebellar		
DQ disease.....		

h) create code

1. nil known	2. nil stated	metoclopramide	3. maxolon	4. morphine
	bactrim	allopurinol		roxithromycin
5. penicillins	6. Sulphur drugs	7. dapsone		8. rifide
	griseofulvin			
9. aminophylline	10. gisovin	11. thalidomide		12. bleomycin
		phenytoin		sodium valproate
13. phenothiazines	14. multiple	15. dilantin		16. epilim
ranitidine	naproxen	clindamycin		
17. zantac	18. naprosyn	19. dalacin C		20. codeine

i) create code

1. nil known	2. nil stated	insertion of long term venous access device	4. tonsillectomy
5. appendectomy	sphincterotomy	incision/drainage of abscess	8. cholecystectomy
insertion/removal of empya	insertion of		biopsy/removal of
9. reservoir	10. cerebral shunt	11. hernia repair	12. lesion
coronary artery bypass graft(s)	repair of fractured bone	15. splenectomy	16. laparotomy
13. graft(s)	14. fractured bone		
17. haemorrhage	knee repair	19. laminectomy	20. hysterectomy

21. bowel resection

j) create code

1. nil known	2. nil stated	3. anaemia	↓/poor appetite
unsteady/abnormal gait			↓ oral intake
unstable on feet	bruising/bleeding	chest tightness	4. anorexia
5. ataxia			deterioration of mental function
	spitum production		memory/concentration impairment
fecal impaction/constipation	10. cough	11. dehydration	disorientated/confusion
	decreased level of consciousness/drowsy	lightheadedness	8. cognitive deficit/mental slowing
13. diarrhoea	14. unconscious	15. dizziness	12. dysphagia
flush/rigor/chill	occult blood in stool	frail, generally unwell	
17. febrile/fever	AR/GIT bleed		
	18. hematemesis	19. weakness	20. haemoptysis

- 21 hallucinations ^{hepato/spleno} 22 -megaly 23 headache 24 glycaemia ^{hypo/hyper}
 hyper 25 -ventilation 26 incontinence ^{fecal/urinary} 27 increased girth ^{abdo distension/} 28 involuntary movements ^{hyper/dys-kinesia}
 29 jaundice 30 effusion ^{joint} 31 lethargy/lethargy ^{fatigue/exhaustion} 32 lymphadenopathy ^{malaise/tired/} 33 clasp, pain 34 nausea 35 paresthesia ^{enlarged gland/} 36 neutropenia ^{lymphadenopathy}
 37 oedema 38 pain 39 pallor 40 pancytopenia ^{myelosuppression}
 paralysis/palsy/ 41 oral weakness 42 psychosis 43 blocked nose 44 movement ^{restricted}
 45 mobilisation 46 sinusitis 47 pruritis 48 excretion ^{skin}
 fit(s) 49 seizures 50 urinary symptoms 51 vomiting 52 impairment ^{visual}
 weight loss/ 53 cachexia 54 ↓ urine output 55 sweats 56 tachypnoea ^{shortness of breath}
 57 discomfort 58 photophobia 59 belabour 60 symptoms ^{dyspnoea}
 hyper/hypo 61 calcemia 62 symptoms 63 hypoxia 64 dysphasia ^{gastro}
 thrombo 65 -Cytopenia 66 papilloedema 67 balance 68 symptoms ^{intestinal tract}
 abnormal liver 69 tests 70 acacia 71 symptoms 72 palpitations ^{trans ischaemic attack/}
 73 cardiomegaly 74 tachycardia 75 hypotension 76 polydipsia ^{neurological}
 blackout/ 77 collapse 78 pressure 79 and pains 80 euphoria ^{cardiac ectopic}
 faint/ 81 insomnia 82 cold 83 hiccups 84 steatorrhea ^{reflux}
 disturbed 85 hypertension 86 mass 87 tumor 88 ascites ^{steatorrhea}
 sleep pattern/

k) create code or use 1f, 1g, 1h, 1i, 1j.

- | | | | |
|--|----------------------------------|--|--|
| 1. nil known
chest pain a/w
respirations/cough | 2. nil stated
shoulder | 3. lower/abd/epigastric/right upper quadrant pain/tenderness | 4. back pain/tenderness |
| 5. pleuritic pain | 6. axilla | 7. neck
due to test | 8. chest cardiac
angina
perforated
proctalgia |
| 9. ear
not pleuritic
not cardiac | 10. throat | 11. or treatment | 12. rectum, anus |
| 13. chest | 14. general aches
wrist, knee | 15. sacrum | 16. groin |
| 17. foot/feet
oral/dental
gums | 18. joint(s) | 19. eye | 20. face |
| 21. mouth | 22. buttock | 23. testicle(s) | |

l) state NS or create code

- | | | | |
|-------------------|-----------------------------|------------------|-------------------------|
| restless | irritable | hostile | stressed
anxious |
| 1. agitated | 2. angry | 3. aggressive | 4. distressed |
| 5. grief issues | despondent | sick of...../ | loss of confidence/ |
| teary/ | depressed mood | frustrated | frightened/apprehensive |
| 9. crying | flat affect
↓ motivation | worried | ap |
| 10. withdrawn | 11. concerned | 12. vague/vacant | |
| 13. bored | shaken | in good | |
| 14. upset | shocked | spirits | |
| non-compliant | sad/miserable | acute/ | |
| 17. uncooperative | 18. unhappy | adjustment | |
| hypomanic | 19. uncommunicative | reaction | |
| 21. manic | 22. motivated | 23. alert | 24. delusional |
| 25. lonely | 26. demanding | 27. disappointed | |

m) use reference for 1f, 1g, 1j.

n) create code or use 1f, 1g, 1h, 1j, 1k, 1l or NK/NS.

o) circle Y/N for all

state other treatments or 0

for self, carer, GCN, clinic and GP - tick, N/S or dash if not applicable

p) state date or circle NK.

SECTION 2

a) state CHC, create code for N.S.W. area health service and other

- | | | | |
|-----------------|--------------------------------|---------------------------|---------------------------|
| 1. nil stated | 2. E.S.A.H.S | 3. C.S.A.H.S | 4. S.S.A.H.S |
| 5. N.S.A.H.S | 6. Central Coast | 7. W.S.A.H.S | 8. S.W.S.A.H.S |
| 9. Westworth | 10. Hunter | 11. Illawarra | 12. North Coast |
| 13. New England | 14. Central West
Nsw Prison | 15. Orana and
Far west | 16. South Coast |
| 17. South West | 18. Medical Services | 19. Queensland | 20. A.C.T |
| 21. Victoria | 22. South
Australia | 23. Western
Australia | 24. Northern
Territory |
| 25. Tasmania | 26. Other | | |

For other, state country referred to

b) state number

c) circle

d) circle Y/N, tick or N/S, state other or dash for not applicable

e), f), g), h) circle

SECTION 3

a) circle or state d/m/y

b), c) circle or use reference code

d) create code

- | | | | |
|---------|-----------|----------------|---------------|
| 1. male | 2. female | 3. transgender | 4. not stated |
|---------|-----------|----------------|---------------|

e) state post code

f), g), h), i) circle

j) create code

- | | | | |
|--------------|---------------|----------------|---------------|
| 1. nil known | 2. nil stated | 3. partner | 4. friend(s) |
| 5. parent(s) | 6. sibling(s) | 7. relative(s) | 8. flatmates) |
| 9. offspring | 10. self only | 11. other | |

k) create code

1. nil known... 2. nil stated... 3. partner... 4. friend...
5. parent... 6. sibling... 7. relative... 8. offspring...
9. other...

l), m) circle

n), o) create code

1. nil known... 2. nil stated... 3. injecting drug use... 4. heroin...
5. cannabis... 6. benzodiazepines... 7. amphetamine... 8. methadone...
9. alcohol... 10. drugs... 11. sedatives... 12. pills...
13. polydrug... 14. drug user... 15. nicotine... 16. cocaine...
17. angel dust... 18. morphine...

p), q), circle

r) circle or state other

s) circle

t) circle or state other

u), v), state comment

APPENDIX E

COMMENTS DURING DATA COLLECTION (4)

GENERAL

If "nil stated" was written on the CNRF, it was entered as "nil known" on the D.C.F. for the specific variable. If there was no information written on the CNRF for a specific variable, "nil stated" was entered on the D.C.F.

CODE: Client Code form available only to researcher.

SECTION 1

a) Date of Admission:

b) Date of Referral: Phone referral may have been made earlier

b) Date of Discharge: If CNRF was written prior to client's discharge, the date was entered on the D.C.F. with "?" to signify date of Gate Pass or expected discharge

c) Year of HIV Diagnosis: Only year available (not date)

d) Last CD4 Count: Date not available. May not be current.

e) Weight: Most recently documented weight during admission

f) Past AIDS/HIV Related Diagnoses: Numerical coding Based

on the categories of the 1993 Revised Classification of the CDC. Past diagnoses may persist or recur as a current problem. Bacterial chest infection may not be differentiated from bacterial pneumonia by the documented diagnosis. Not classified as HIV Cat. C. Illness documented x2 pneumonia. Detail of HSV not documented in detail. Some may be chronic ulcers of >1 month duration and therefore be a HIV Cat C. Illness...

g) Past Other Diagnoses: Seborrheic dermatitis may be related to HIV and is coded separately to other types of dermatitis. Documented dermatitis on the C.N.R.F may be seborrheic (gn, gai). In IgT the type of hepatitis not differentiated on the D.C.F. Some entries in Ig may be HIV related, but not diagnosed or coded as such eg sclerosing cholangitis, transverse myelitis, HSV, cardiomyopathy, pyomyositis, gastritis, HIV retinopathy.

lgx may = l13 lg CO = lg CX. May include diagnoses,
signs or symptoms. Anaemia is coded in lg and lj.
Depression refers to psychiatric diagnosis

h) Allergies: Refers to allergies and intolerances eg. Bone
marrow depression.

i) Past Surgery:

j) Symptoms/Signs During Admission: Discomfort (lj57) or
dysphagia (lj12) not associated with pain unless
specifically mentioned. May include diagnoses, signs
or symptoms.

k) Cause/Site of pain: Further information re lj 38, 12, 23,
33, 35, 50, 69, 71 and 79. Cause of pain may be a
presumption of the researcher by comparing pain
symptom to ICD New Dx/RFA, pain site and/or

subsequent resolution of pain following treatment.

DPsycho/Emotional Status: 'nil known' variable not used.

1.16, depressed mood may include clients with undocumented psychiatric diagnosis of depression.

m) New Diagnoses/Reasons for Admission: May be the same as a past diagnoses or symptom.

n) Highlighted Ongoing Issues on Discharge: Only refers to those specifically highlighted on C.N.R.F.

o) Treatments on Discharge: Self, Carer, G.C.N., Clinic, G.P: Only refers to those documented on CNRF

No. of oral meds: Those transferred to CNRF from discharge prescription only. Client may take additional meds.

Subcut meds:

I.V. meds:

Ganciclovir:

Foscarnet:

Amphotericin:

Other antibiotic:

IMI meds:

No. of topical meds:

N/G /Enteral feeds:

Per rectum meds:

Nebulised meds:

Puffers:

Aural meds:

Dressings:

Eye meds:

Physio:

Other: *eg. methadone maintenance program (not on script)*

p) Date of Death: *This information not on C.N.R.F.*

Details used from National HWR Registry + PHM data base.

If incomplete date available, 15 used for missing value

for day and 6 used for missing value of month.

SECTION 2

a) C.H.C. Referred to: *During study period Redfern CHC*

relocated to Newtown CMC. Eastgardens CMC relocated to RSSCMC

Area of Referral: Area Health Service at time of referral. Boundaries of some AMSs have changed.

State Other:

b) No. of Referrals so far to this Community Nursing Team: Only.....
within the study period. Previous referrals may have
been made known as referral 1, referral 2 etc.

c) New Client to this Community Nursing Team: New client
ever. i.e. initial referral.

d) Specific Requests Made to G.C.N.s Refers to requests documented
on C.N.R.F. Not conclusive. G.C.N. will do more than
is formally requested.

Monitor symptoms: ongoing physical assessment

Emotional support:

Home assessment: assessment of home environment
eg. safety, suitability and client's management of ADL.

Fill dossette box:

Give subcut meds:

I.V. meds:

Provide equipment

Encourage medical f/u:

Monitor dietary intake:

control:

Chest physio:

Liaise with M.O, HCW:

Give IMI/SC meds:

Increase supports:

Palliation/Terminal care:

Assistance ADLs:

Dressings:

Pressure area care:

Co-ordinate services:

Encourage autonomy:

Mouth care:

Other

Support client/carer to:

Fill dossette Box:

Give IMI/SC meds:

N/G / Enteral feeds:

Chest physio:

Give oral meds:

Assistance with ADLs:

Dressings:

Pressure area care:

Mouth care:

Palliative/Terminal care:

IV meds:

Encourage autonomy:

Other

e)Mobility:

Not stated

Immobile

Ambulant

With ch

As tabled/ is

Independent/Ass tanc

With d/W thout d/N tated if aid used

Other

d) P Care under heading of ADL on CNRF

No ted

Indep de t

D pen en

Supr

As

A. d. ted/

Oth

g)H Dut under heading of ADL on CNRF

No tate

Indepe nt

Dependent

Supervision

Assistance

As tolerated/able

Other

h)Contact Details of S/W Stated:

SECTION 3

a)D.O.B:

b)Nationality:

c)Language:

d)Sex:

e)Res. Postcode: obtained from telephone book if

not stated on referral form.

f)Pension: presumed not to be on pension if working

Does not include sickness benefits.

g)Living alone:

h)Sexuality: If not specifically stated, may be deduced

if the sex of partner is stated.

.....

i)Phone:

j)Living With: Partner may be referred to as friend

If living with more than one person, first mentioned entered. If living with partner and offspring, partner entered.

k>Contact Person Relationship: Partner may be referred to as friend.

l)'Friend' Also Stated to be Same Sex Partner: Stated as partner in current or previous referral.

m)Orientated:.....

n)Past Unprescribed Substance Use: Refers to lifestyle

patterns and 'heavy' alcohol intake. 'heavy' not

defined. Absence of documentation does not exclude history.

o)Recent Unprescribed Substance Use: As for 3n

.....

p)Current Cigarette Smoker:

q)Current Alcohol:

r)Other Community Services Accepted: Includes only those
stated. The client may access other services listed

s)Client Given Names of GPs: usually only stated on
CNRF if done.

t)Social Worker Help: emotional = counselling.....

u)Specific Comment: Refers to what is stated on the
CNRF only. eg. quotes.

v)Researcher Comment: observational comments.....
made by researcher on reading C.N.R.F.
during data collection. eg. difficult to read.

ADDITIONAL COMMENTS: eg. ij. variables were
created from the raw data and entered on the
D.C.F. Different terms may be used for the
same sign, symptom, illness or condition.....

These, and similar variables may be grouped together using the one code.

Similar or identical variables may be found in lg and lj. Codes in lg will be used specifically to answer lg. Codes in lj will be used specifically to answer lj.

Any repeated variable code in one question will be addressed on entry to spreadsheet or on data analysis of lj11, lj16.

APPENDIX F

HIV-related illnesses

Code Illness

- B 1 Oral candidiasis
- B 2 Oral pharyngeal candidiasis
- B 3 Persistent vulvovaginal candidiasis (persistent, recurrent or unresponsive to therapy)
- B 4 Multidermatomal Herpes zoster (single episode, > 1 dermatome)
- B 5 Recurrent Herpes zoster (2 distinct episodes, single dermatome)
- B 6 Listeriosis
- B 7 Pelvic inflammatory disease
- B 8 Cervical dysplasia (moderate to severe)
- B 9 Cervical carcinoma in situ
- B 10 Bacillary angiomatosis
- B 11 Oral hairy leukoplakia
- B 12 Idiopathic thrombocytopenic purpura
- B 13 Peripheral neuropathy
- B 14 Persistent fever (> 1 month duration)
- B 15 Persistent diarrhoea (> 1 month duration)
- B 16 Molluscum contagiosum

Code Illness

- C 1 Cervical cancer, invasive
- C 2 Kaposi's sarcoma
- C 3 Presumptive Kaposi's sarcoma
- C 4 Burkitt's lymphoma (or equivalent term)
- C 5 Immunoblastic lymphoma (or equivalent term)
- C 6 Primary lymphoma of brain
- C 7 HIV-related encephalopathy
- C 8 HIV wasting syndrome
- C 9 Candidiasis of bronchi
- C 10 Candidiasis of trachea
- C 11 Candidiasis of lungs
- C 12 Oesophageal candidiasis
- C 13 Presumptive oesophageal candidiasis
- C 14 Coccidioidomycosis, disseminated or extrapulmonary
- C 15 Cryptosporidiosis, chronic intestinal

- C 16 Cytomegalovirus disease (other than liver, spleen or nodes)
- C 17 Cytomegalovirus retinitis
- C 18 Herpes simplex: chronic ulcer(s) (> 1 month duration)
- C 19 Herpes simplex bronchitis
- C 20 Herpes simplex pneumonitis
- C 21 Herpes simplex oesophagitis
- C 22 Histoplasmosis, disseminated or extrapulmonary
- C 23 Isosporiasis, chronic intestinal
- C 24 *M. avium* complex or *M. Kanasii*, disseminated or extrapulmonary
- C 25 Disseminated *M. tuberculosis*
- C 26 Presumptive mycobacteriosis
- C 27 *Mycobacterium*, other or unidentified species, disseminated or extrapulmonary
- C 28 *Pneumocystis carinii* pneumonia
- C 29 Presumptive *Pneumocystis carinii* pneumonia
- C 30 Recurrent pneumonia (≥ 2 distinct episodes)
- C 31 Presumptive recurrent pneumonia
- C 32 Progressive multifocal leucoencephalopathy
- C 33 Recurrent *Salmonella* septicaemia (≥ 2 distinct episodes)
- C 34 Toxoplasmosis of the brain
- C 35 Pulmonary *M. tuberculosis*
- C 36 Cryptococcosis, extrapulmonary

Code Illness

- D 1 Microsporidiosis
- D 2 Aspergillosis
- D 3 Nocardiasis
- D 4 Leishmaniasis

APPENDIX G

DATA COLLECTION FORM(1)

CODE: /

SECTION 1

a)Date of Admission: b)Date of Discharge:

c)Year of HIV Diagnosis: d)Recent CD4 Count: e)Weight:

f)Past HIV-related Illnesses:*c* 1)..... 2)..... 3)..... 4)..... 5)..... 6).....
7)..... 8)..... 9).....10).....11).....12).

g)Past other Illnesses:*c* 1)..... 2)..... 3)..... 4)..... 5)..... 6).....

h)Allergies: NK / NS 1)..... 2)..... 3)....

i)Past Surgery: NK / NS 1)..... 2)..... 3).

j)Symptoms/Signs During Admission:*c* 1)..... 2)..... 3)..... 4)..... 5)..... 6).....
7)..... 8)..... 9).....10).....11).....12)....

k)New Diagnoses:*c* 1)..... 2)..... 3)..... 4)..... 5)..... 6).....

D)Treatments on Discharge:	Self	Carer	G.C.N.	Clinic
No. of oral meds:
Subcut meds:
I.V. meds: Y/N				
Ganciclovir Y/N
Foscarnet Y/N
Amphotericin Y/N			
Other Antibiotic		
No. of topical meds:		
N/G Feeds: Y/N		
Other 1:		
Other 2:		

m)Date of death:

SECTION 2

a)C.H.C. Referred to: Area of Referral:*c*
State Other:

b)No. of referrals so far to this Community Nursing Team:

c) Specific Requests made to G.C.N.s

Monitor symptoms: Emotional support: Home Assessment:
Fill dosette box: Give subcut meds: Give I.V. meds:
Provide equipment: Other 1:

Other 2: Other 3:

Support client/carer to:

Manage N/G feeds: Give oral meds: Give subcut meds:
Give I.V. meds: Other 1:

Other 2: Other 3:

d) Mobility: Not stated Immobile
Independent/Assistance With aid/Without aid/Not stated if aid used

e) Personal care:

Not stated Independent Dependent Supervision Assistance

f) Home duties:

Not stated Independent Dependent Supervision Assistance

SECTION 3

a) D.O.B: NK NS **b) Nationality:** NK NS *c*

c) Language: NK NS *c*

d) Sex: M/F/T/NS **e) Res. postcode:** **f) Pension:** Y/N/NK/NS

g) Living alone: Y/N/NK/NS **h) Sexuality:** HET/HOM/BI/NK/NS

i) Phone: Y/N/NK/NS

j) Living with: NK NS Partner Friend(s) Parent(s)

Sibling(s) Relative(s) Flatmate(s) Offspring Other:

k) Contact person relationship: NK NS Partner Friend Parent
Sibling Relative Other: **D) Orientated:** Y/N/NK/NS

m) Past/recent unprescribed substance use: NK NS Heroin Cannabis
Benzodiazepine Amphetamine Methadone Other 1:

n) Past/recent heavy alcohol intake: NK NS Y N

o) Other community services accepted:

NK NS Physio Home Care M.O.W C.S.N Ankali Transport

O.T S.W Local G.P Other 1: Other 2:

p)Social Worker help:NK NS Financial Accommodation Emotional

Other 1: Other 2: Other 3:

q)Specific Comment 1:

Specific Comment 2:

Specific Comment 3:

Specific Comment 4:

Specific Comment 5:

Specific Comment 6:

Specific Comment 7:

Specific Comment 8:

r)Researcher Comment 1:

Researcher Comment 2:

Reaearcher Comment 3:

APPENDIX H



AUSTRALIAN CATHOLIC UNIVERSITY

Ms Adrienne Lucey
5/70 / Albion Street
Randwick NSW 2031

26 February 1996

Dear Ms Lucey

Thank you for your letter of 25 January 1996 regarding your Ethics Clearance for the project 'Retrospective Review of Referrals From a HIV Unit to Community Nursing Services 1991 - 1995' (Research Ethics Committee Register Number N95 - 040.)

Your letter was considered by the Committee at its meeting on 2 February 1996. The Committee noted the increase in sample size for your research project.

Yours sincerely

Elizabeth Linley
Executive Officer
Research Projects Ethics Committee



AUSTRALIAN CATHOLIC UNIVERSITY

Ms Adrienne Lucey
5/70 Albion Street
Randwick NSW 2031

22 August 1995

Dear Ms Lucey

The Research Projects Ethics Committee has considered your application for an ethics clearance for the following project:

**Analysis of Community Nursing Referral Forms Used for Patients
Discharged from a Human Immunodeficiency (H.I.V.) Unit Between 1991
and 1995.**

Ethics clearance will be granted for the project subject to the following conditions as stipulated by the Research Projects Ethics Committee:

- 1) the data be deidentified and the manner in which it is deidentified, be satisfactorily explained to the Committee. (I understand Dr Tobin has spoken to you regarding this matter.)
- 2) because of the relative lack of experience of this Committee in the area of research on people who have died of HIV/AIDS, the project also receive the approval of each of the following Committees with the South Eastern Sydney Area Health Service:
 - i) Nursing Research Committee
 - ii) HIV Research Committee
 - iii) Research Ethics Committee

Could you please inform the Committee of the outcome of these conditions.

Yours sincerely

Elizabeth Linley
Executive Officer
**Research Projects Ethics Committee
(NSW Division)**

AUSTRALIAN CATHOLIC UNIVERSITY

New South Wales Division

RESEARCH PROJECTS ETHICS COMMITTEE

ETHICS CLEARANCE FOR A RESEARCH PROJECT – APPROVAL FORM

Investigator: Ms Adrienne Lucey
Supervisor: Dr Brian Bicknell

The Research Projects Ethics Committee considered the protocol for your project:

**Analysis of Community Nursing Referral Forms Used for Patients
Discharged from a Human Immunodeficiency Virus (HIV) Unit between
1991 and 1995**

on 16 June 1995 and decided that the application be resubmitted to the Committee, with particular attention given to the following:

- a) that a letter be sent to the next of kin seeking permission to research the medical records of the deceased persons
- b) that a password be used on the computer to prevent access by persons other than the researcher
- c) that no names be included on any research data
- d) any other requirements as a result of clarification of some of the concerns of the Committee

Please resubmit the application and return it to reach the Executive Officer, Research Projects Ethics Committee, by Monday 17 July 1995

Signed: Elizbeth Linley
Executive Officer, Research Projects Ethics Committee
New South Wales Division

Date: 23/6/95

AUSTRALIAN CATHOLIC UNIVERSITY

New South Wales Division

RESEARCH PROJECTS ETHICS COMMITTEE

ETHICS CLEARANCE FOR A RESEARCH PROJECT – APPROVAL FORM

Investigator: ✓ Ms Adrienne Lucey
Supervisor: Dr Brian Bicknell

The Research Projects Ethics Committee considered the protocol for your project:

**Analysis of Community Nursing Referral Forms Used for Patients
Discharged from a Human Immunodeficiency Virus (HIV) Unit between
1991 and 1995**

on 25 July 1995 and decided that the application be resubmitted to the Committee, with particular attention given to the following:

- 1) that Ms Lucey ask the Hospital for permission to use the medical records of these patients in a de-identified manner and that Ms Lucey clarify the fact that, in her research, she will be dealing only with de-identified data;
- 2) that Ms Lucey ensure that the data will be stored in a manner which is inaccessible to anyone other than herself;
- 3) that Ms Lucey ensure that the consent of the next of kin be obtained since records will be used for a purpose different from that for which they were originally established;
- 4) that the Consent Form be printed on University letterhead, that it follow the format set out in the University's Guidelines, and that it contain the information as set out in the attached.

Please resubmit the application and return it to reach the Executive Officer, Research Projects Ethics Committee, by Friday 11 August 1995

Signed: Elyabeth Linley
Executive Officer, Research Projects Ethics Committee
New South Wales Division

Date: 4/4/95

A Lucey

Informed Consent

Proposed wording

You are invited to give your consent for the inclusion of medical information relating toin a research study into an Analysis of Community Nursing Referral Forms Used For Patients Discharged From a Hospital Ward/Unit Between 1991 - 1995. The Study is being conducted by Adrienne Lucey, Clinical Nurse Consultant, Community Health, Eastern Sydney Area Health Service.

At present the Australian literature that identifies information regarding the referral of patients to community nurses and the effect referral has on hospitalisation, discharge planning and their ongoing management is deficient in certain areas. The object..... systems.

next paragraph - no change

Your consent for the inclusion of the above named deceased friend/relative in this study is entirely voluntary: you are not obliged to consent and, if you do consent, you can change your mind at any time.

next paragraph - no change. Add the following

However, by law Adrienne Lucey is not at liberty to disclose details of the nature of the ward in which your friend/relative was treated, nor to otherwise disclose details of the nature of your friend's/relative's medical condition as such information is confidential.

If you have any concerns about the conduct of this research study, you can write to:

The Chair
Research Projects Ethics Committee
C/- Research Office
179 Albert Road
Strathfield 2135

APPENDIX I

EASTERN SYDNEY AREA HEALTH SERVICE

SOUTH EASTERN SYDNEY AREA HEALTH SERVICE - Eastern Section

NURSING RESEARCH COMMITTEE

20 September, 1995

All correspondence to:
Chief Executive Officer
Eastern Sydney Area Health Service
Administrative Centre
Cnr High and Avoca Streets
RANDWICK NSW 2031
Facsimile: (02) 398-7395
Telephone: (02) 399-0111
Extension: 399 1014
KB:ds

Ms Adrienne Lucey
5/70 Albion Street
RANDWICK NSW 2031

Dear Ms Lucey

The Nursing Research Committee is in receipt of your letter dated 19 September, 1995 to supply information in response to concerns revised by the Committee.

Following consideration of the revised material Executive Approval has been given for the above study on 20 September, 1995.

We understand that the above study will go before the South Eastern Sydney Area Health Service Research Ethics Committee at its meeting on 26 September, 1995 for final approval.

The Nursing Research Committee wishes you well with your study.

Please find enclosed a copy of the Nursing Research Committee's original letter to you after their initial review of this study for your records.

Yours sincerely



Kim Breheny
Research Ethics Co-ordinator

Incorporating:

The Sydney Hospital
The Sydney Eye Hospital
The Prince Henry Hospital
The Prince of Wales Hospital
The Prince of Wales Children's Hospital
The Royal South Sydney Hospital

The Royal Hospital for Women
The Langton Centre
Community Health Services and Programs
Administrative Responsibility for:
The Gower Wilson Memorial Hospital,
Lord Howe Island

Associated Third Schedule Hospitals are:

St Vincent's Hospital Sydney Limited
Sacred Heart Hospice
War Memorial Hospital (Waverley)
Scarba Family Centre



EASTERN SYDNEY AREA HEALTH SERVICE Nursing Research Committee

"Examining Nursing Practice"

Our Reference:

Your Reference:

Enquiries to:

Chairperson: Mrs Barbara Shadbolt
Director of Nursing Services
Eastern Sydney Area Health Service
Edmund Blacket Building
Prince of Wales Hospital
High Street, Randwick NSW 2031

Telephone: (02) 399 2600
Facsimile: (02) 398 8296

BGS:at
29th August 1995

Ms Adrienne Lacey
5/70 Albion Street
RANDWICK NSW 2031

Dear Ms. Lacey,

95NR 005 "Retrospective Review of Referrals from a HIV Unit to Community Nursing Services 1991-1995".

The Nursing Research Committee at its meeting on 23rd August, 1995, considered your research proposal and passed the project subject to the following modifications:

- the Committee noted that the proposal had been considered by the HIV Research Committee and the Australian Catholic University Research Projects Ethics Committee particularly in regard to whether or not a consent should be obtained.
- the wording of the 'consent' section of the body of the proposal is still confusing to read. The Committee suggested that a statement be included which clarifies that it is not intended to obtain consent and that the HIV Research Committee advise.
- reference to the method of safe storage and disposal of data is required.

The proposal was approved subject to these changes being made.

Yours sincerely,

Mrs. B.G. Shadbolt
Chairperson
Nursing Research Committee

APPENDIX J



SOUTH EASTERN SYDNEY AREA HEALTH SERVICE

RESEARCH ETHICS COMMITTEE - Eastern Section

Room G71, EBB
Cnr High & Avoca Strs
RANDWICK NSW 2031
Tel: 9382 3587
Fax: 9382 2813

28 June 2000

Ms A. Lucey, CNC
501\2 Springfield Ave,
Potts Point
NSW 2011

Dear Ms Lucey

**Re: Retrospective Review of Referrals from a HIV Unit to Community Nursing Services,
1993-1995**

The Research Ethics Committee at its meeting of 27 June 2000, received and noted your Annual Report dated 3 May 2000 and request for an extension of 12 months, and this request was approved.

Yours sincerely

**Kim Breheny
Research Ethics Officer**



SOUTH EASTERN SYDNEY AREA HEALTH SERVICE

RESEARCH ETHICS COMMITTEE - Eastern Section

Room G71, EBB
Cnr High & Avoca Strs
Randwick NSW 2031
Tel: 9382 3583
Fax: 9382 2813

24 February, 1999

Ms A. Lucey
c/- Generalist Team
Royal South Sydney Community Health Complex

Dear Ms Lucey

**Re: Retrospective Review of Referrals from a HIV Unit to Community Nursing Services,
1993 - 1995. Ref: 95/137.**

The Research Ethics Committee at its meeting of 23 February, 1999 received and noted your **Annual Progress Report dated 21 December, 1998 and approved your request for an extension of approval for 12 months** for the above study.

Yours sincerely

Kim Breheny
Research Ethics Officer



SOUTH EASTERN SYDNEY AREA HEALTH SERVICE

RESEARCH ETHICS COMMITTEE - Eastern Section

Room G71, EBB
Cnr High & Avoca Strs
Randwick NSW 2031
Tel: 9382 3583
Fax: 9382 2813

4 November, 1998

Ms A. Lucey
Community Health Services and Programs
Royal South Sydney Complex

Dear Ms Lucey

Re: **Retrospective review of referrals from a HIV unit to community nursing services.
1991-1995.. Ref: 95/137.**

According to our records this study was submitted to the Research Ethics Committee for approval in 1995.

Once Ethics Approval has been given an Annual Progress Report **must** be submitted 12 months after the date of approval and every 12 months **and on completion of the study.**

If you have already sent an annual report in 1998 for the above study please disregard this letter. If not, please complete the attached progress report and return it to this office as soon as possible.

Yours sincerely

Kim Breheny
Research Ethics Co-ordinator



SOUTH EASTERN SYDNEY AREA HEALTH SERVICE

RESEARCH ETHICS COMMITTEE - Eastern Section

Administration Centre
Cnr High & Avoca Strs
Randwick NSW 2031
Tel: 9382 3583
Fax: 9382 2813

18 December, 1996

Ms A. Lucey
c/- HIV CNC, Generalist Team
Royal South Sydney Community Health Complex
Joynton Avenue
ZETLAND NSW 2017

Dear Ms Lucey

Re: Retrospective Review of Referral Forms from a HIV Unit to Community Nursing Services 1993 - 1995. Ref: 95/137.

The Research Ethics Committee at its meeting of 17 December, 1996 received and noted your Annual Report dated 31 October, 1996.

The Committee also approved your application for extension of approval until July, 1997.

Yours sincerely

Kim Breheny
Research Ethics Co-ordinator



**SOUTH EASTERN SYDNEY
AREA HEALTH SERVICE**

RESEARCH ETHICS COMMITTEE - Eastern Section

Administration Centre
Cnr High & Avoca Strs
Randwick NSW 2031
Tel: 382 3583
Fax: 398 8296

4 October, 1996

Ms A. Lucey
Community Health Services and Programmes
Royal South Sydney Hospital Complex
ZETLAND NSW 2017

Dear Ms A. Lucey

**Re: Retrospective Review of Referrals From A HIV Unit to Community Nursing
Services. 1991 - 1995. Ref: 95/137.**

According to our records Research Ethics Committee approval was given for this study in September, 1995.

Once Ethics Approval has been given an Annual Progress Report **must** be submitted 12 months after the date of approval and every 12 months from there on until and on completion of the study.

If you have already sent in an annual report for the above study please disregard this letter. If not, please submit your report as soon as possible.

Enclosed is a report form for your convenience.

Yours sincerely

Kim Breheny
Research Ethics Co-ordinator



SOUTH EASTERN SYDNEY
AREA HEALTH SERVICE

RESEARCH ETHICS COMMITTEE - Eastern Section

Administration Centre
Cnr High & Avoca Strs
Randwick NSW 2031
Tel: 382 3583
Fax: 398 8296

28 February, 1996

Ms Adrienne Lucey
5/70 Albion Street
RANDWICK NSW 2031

Dear Ms Lucey

Re: Retrospective Review of Referrals From a HIV Unit to Community Nursing Services 1991 - 1995. Ref: 95/137.

The Research Ethics Committee at its meeting of 27 February, 1996 considered and approved the amendment to the sample size used in the above project.

Please note that any approval, relates to the ethical content of the trial, and individual arrangements should be negotiated with the Heads of Departments in those situations where the use of their resources is involved.

The Committee wishes you well with the continuation of your study.

Yours sincerely

Kim Breheny
Research Ethics Co-ordinator

EASTERN SYDNEY AREA HEALTH SERVICE

SOUTH EASTERN SYDNEY AREA HEALTH SERVICE - Eastern Section

RESEARCH ETHICS COMMITTEE

27 September, 1995

All correspondence to:
Chief Executive Officer
Eastern Sydney Area Health Service
Administrative Centre
Cnr High and Avoca Streets
RANDWICK NSW 2031
Facsimile: (02) 398-7395
Telephone: (02) 399-0111
Extension: 382 3583
KB:ds

Ms A. Lucey
5/70 Albion Street
RANDWICK NSW 2031

Dear Ms Lucey

**Re. Retrospective Review of Referrals From a HIV Unit to Community
Nursing Services 1991 - 1995. Ref: 95/137.**

The Research Ethics Committee at its meeting of 26 September, 1995 considered and approved the above study.

This study has been allocated the reference number **95/137**. This reference must be quoted in all correspondence with the Committee.

Please note that any approval, relates to the ethical content of the trial, and individual arrangements should be negotiated with the Heads of Departments in those situations where the use of their resources is involved.

In accordance with the National Health and Medical Research Council guidelines, the Committee requires you to provide a progress report annually and on completion of the study.

You may commence your study and the Committee wishes you well.

Yours sincerely



Kim Breheny
Research Ethics Committee

Incorporating:

The Sydney Hospital
The Sydney Eye Hospital
The Prince Henry Hospital
The Prince of Wales Hospital
The Prince of Wales Children's Hospital
The Royal South Sydney Hospital

The Royal Hospital for Women
The Langton Centre
Community Health Services and Programs
Administrative Responsibility for:
The Gower Wilson Memorial Hospital,
Lord Howe Island

Associated Third Schedule Hospitals are:

St Vincent's Hospital Sydney Limited
Sacred Heart Hospice
War Memorial Hospital (Waverley)
Scarba Family Centre

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APPENDIX K



21 November 1995

Professor John Kaldor
National Centre in HIV Epidemiology and
Clinical Research
Faculty of Medicine, UNSW
2nd Floor
St Vincent's Hospital Medical Centre
376 Victoria St.
Sydney NSW 2010

RE: Research Project of Ms Adrienne Lucey

Dear Professor Kaldor,

Thank you for your letter dated 8 November 1995 concerning the above research project.

I am pleased to authorise you to release information sufficient to confirm the dates of death of the people in the study sample who have died.

This information is already held and owned by Prince Henry Hospital. I acknowledge the fact that this is merely confirming the dates of death already available to Ms Lucey and that the data you hold may well be more complete than that available to her.

If you have any queries on this matter do not hesitate to contact me on 391 9195

Yours sincerely,

A handwritten signature in blue ink, appearing to read "John G Brown". The signature is written in a cursive, flowing style.

John G Brown
A/Manager Surveillance Section
AIDS/Infectious Diseases Branch