A Profile of Informal Carers in South Africa

by

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Abstract

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Demographic and epidemiological change has resulted globally in changes in population and individual health, which, in turn, have resulted in changing care needs. Demographic change in South Africa, mainly through a confluence of declining fertility rates and pre-AIDS increases in life expectancy, has produced an ageing population that is expected to continue ageing for at least the next 10 to 15 years. Currently, South Africa's older population (60 years+) has a much higher annual average percent growth rate than the total population. Having more older persons than ever before implies increased prevalence of frailty, chronic disease and disability through a tendency of declining physical, mental and cognitive functional capacities—hence meaning a larger demand for care.

The changing age structure of a population is commonly associated with changes in health, disease and cause of death patterns. Recent research indicates an intensive, quadruple burden of disease, with the major addition of HIV/AIDS to persistent pre-transitional conditions, non-communicable conditions, and high rates of injuries—implying an extensive and diverse need for care.

While demographic and epidemiological change have led to an increased demand for care, health system change, shortages in formal public health care delivery, and the spiralling costs of private care have led to decreased availability of formal care. Care-requiring persons therefore may need to rely increasingly on ‘informal care’, defined here as ‘care provided at home to another person who, because of frailty disability or ill-health, cannot manage on his/her own’.

Research on informal care in developed nations is well-established and extensive, but has received very little attention in South Africa where it is not clear how many and who it is that are informal carers. The thesis study has hence been conducted to contribute to the limited research in the field of informal care, aiming to establish the national extent of informal care, and to present a demographic and socio-economic profile of informal carers.

A multi-stage stratified area cluster probability sample of 2704 persons was drawn from free-living adults in a nationally-representative household survey in 2000. Field data were collected during 2611 individual face-to-face interviews. Basic univariate and logistic regression analyses were conducted.

Of the adult population, 27% were found to be informal carers. Significant prevalence differences were found regarding sex, population group, geographic residence, education, employment status, and income. Adjusting for selected demographic characteristics, the significance status and levels of some relationships changed.

It is concluded that informal caregiving is widespread in South Africa. While demographic and epidemiological evidence suggest that the reliance on informal carers is expected to increase, many informal carers are struggling to shoulder the physical, mental and financial burden. A national strategy to focus on informal carers is recommended, to raise awareness about their essential role and value in the health care system; to recognize their contributions to population and individual health; to comprehensively support them; and to assess their needs and concerns through ongoing research.

Key terms

Informal care(r)

Family care(r)

Unpaid care(r)

Home care(r)

South Africa

Demographic transition

Population ageing

Epidemiological transition

Burden of disease

Health transition

Chapter 1

Introduction

1.1 ‘CARE’ AND ‘INFORMAL CARE’ AS REFERRED TO IN THE STUDY

The concept ‘care’ entails a rich semantic value, can be used in various contexts, and often varies in meaning and significance in different societies, cultures, families and individuals. For the purpose of the thesis, ‘care’ refers to the task of attending to another person in the context of frailty, disability or ill-health.

The thesis’s focus is on persons who provide care, not in the context of formal care provided by care professionals, but in the home setting on a daily basis to individuals in need of care beyond that expected for a healthy child or adult. These carers usually are family members, other relatives, spouses, partners, friends and neighbours of the care recipient. They are referred to in the literature as ‘informal carers’, ‘family carers’ or ‘unpaid carers’.

Some tasks or responsibilities in the home setting within the context of persons sharing a household may be referred to as ‘care’, others not. For the purpose of the study, it was therefore necessary to distinguish between ‘caregiving tasks’ and ‘general household or parenting tasks’. Among adults, it is presumed that healthy, able-bodied persons generally have the capability to live their lives independently of help from someone else in performing key activities of daily living (ADLs) and instrumental activities of daily living (IADLs).[1] However, when faced with frailty or moderate to severe disability and ill-health, they may become unable to undertake certain tasks necessary for biological, psychological, social and household upkeep and survival. Such tasks may include obtaining, preparing and consuming food; maintaining personal and home hygiene; maintaining ambulance; and maintaining safety awareness to prevent falls, drowning, burns and other causes of injury, disability or death. When unable to perform some of these activities, an individual needs assistance and support beyond that customarily needed for a healthy, able-bodied adult (WHO, 2002a: 3, 22).

In young children, particularly infants and toddlers, close supervision and considerable help with basic ADLs are routinely required. It may be difficult at times to separate caregiving from parenting behaviour or tasks, but as children grow older, they progressively require less supervision and help, and become more independent. However, children with long-term or permanent conditions at the moderate and severe end of the disability and ill-health spectrum, for example those with paraplegia, blindness or severe neural tube defects, would require additional supervision and help beyond routine parenting tasks (WHO, 2002a: 25).

In the thesis, the term 'care' hence refers to the need for human help that would not customarily be needed for physically, emotionally or mentally healthy adults

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[1] "Activities of daily living" (ADLs) and "instrumental activities of daily living" (IADLs) are terms being used internationally in assessing an individual's functional health. ADLs is "the most commonly-used measure of functional health", summarizing a person's performance in personal care tasks such as eating, walking, dressing, bathing, using the toilet, getting in and out of a bed or chair, and managing a bowel-control device. IADLs summarize a person's performance vis-à-vis his/her environment, including light housework, meal preparation, making a phone call, managing one's money or financial concerns, grocery shopping, and home management (Hooyman & Kiyak, 2002: 103).

and children, a concept that is referred to by the WHO (2002a: 3) as "dependency". Within this meaning of care, three dimensions of care were identified, i.e. duration of care, setting or place of care, and mode of care. These dimensions are captured in Figure 1.

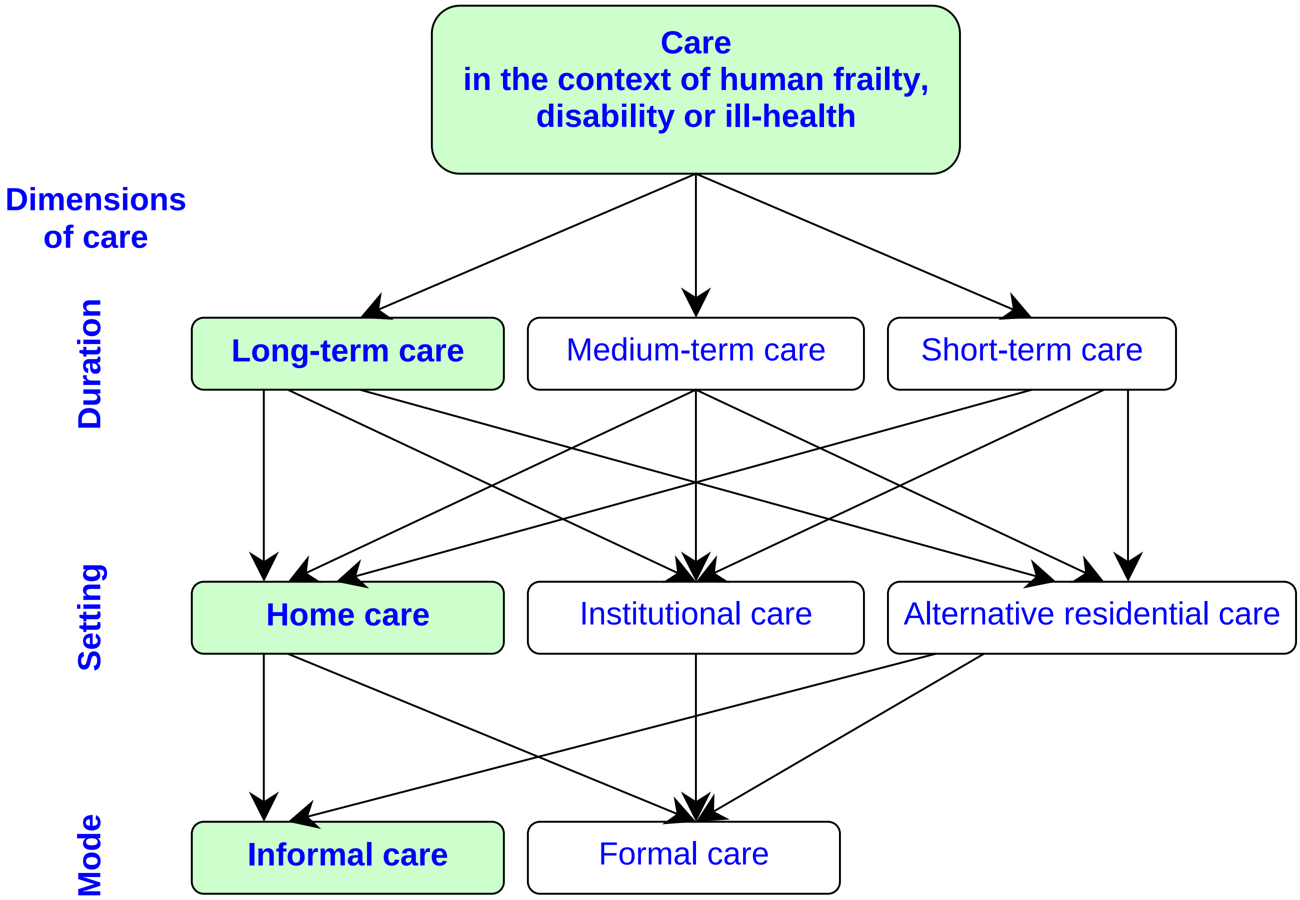

Figure 1.1: A simplistic classification of health and health-related care in the context of human frailty, disability and ill-health[2]

In Figure 1, a distinction is made between long-, medium- and short term care within the duration dimension. In the place-of-care dimension, a distinction is made between home care, institutional care (e.g. in a frail care unit or hospital), and

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[2] Due to differences among and within societies, as well as overlap in the goals and providers of each type of care within the mentioned dimensions, this diagram presents no more than a crude classification of care.

alternative residential care (e.g. in assisted-living homes for partly-dependant persons, or shelters for abandoned and abused older persons). In the mode-of-care dimension, a distinction is made between formal care (e.g. daily morphine administration by a professional nurse) and informal care (e.g. bandaging a wound, or preparing meals by a relative).

The thesis study focuses on 'informal care', which encompasses a wide range of activities, experiences and situations. It may include looking after an adult child with AIDS-related disease, a frail parent with advanced Alzheimer's disease, a young child with severe cerebral palsy, or a blind neighbour. Informal carers usually have a wide variety of tasks and responsibilities in their carer roles, spanning both ADLs and IADLs. These activities may include personal care tasks such as bathing, toileting and feeding the care recipient; health care tasks such as cleaning and dressing wounds; housekeeping tasks; providing emotional support through comforting, encouraging and pacifying; providing transport; and assisting with life management, e.g. managing the care recipient's financial issues and doing shopping. While informal carers are found along a wide age range, and include being young children, teenagers, adults, or older persons, the thesis study is about informal carers 18 years or older.

1.2 BACKGROUND

1.2.1 The Health Transition

The aggregate processes at work in a country's demographic and epidemiological transitions are referred to as the health transition. It refers to the combined changes in fertility, mortality, morbidity, risk factors, cause of death profiles, as well as the health system's response to these (Mosley *et al*., 1993; Frenk *et al*., 1989). The health transition, through the demographic transition, the epidemiological transition, and health sector change in South Africa, form the conceptual background of the thesis study.

1.2.1.1 Demographic change

Due to demographic change—mainly through a confluence of declining fertility rates and pre-AIDS increases in life expectancy—South Africa's population is ageing. The population is expected to continue ageing for at least the short-term future over the next ten to fifteen years, despite shortened average life expectancy resulting from the impact of AIDS (Haldenwang, 2001; Joubert *et al*., 2003). As longevity increases, the prevalence of frailty, chronic disease and disability raises through a tendency of declining physical, mental and cognitive functional capacities in ageing individuals (National Academy of Sciences, 2001; UNFPA, 2002; WHO, 2002c; WHO, 2002d). In this way, the ageing of the South African population contributes to an increasing number of people who need care.

1.2.1.2 Epidemiological change

Careful interpretation of mortality and morbidity data has shown that the South African epidemiological profile has recently built up into a quadruple burden of disease. In addition to the previously-triple burden of a) pre-transitional conditions related to under-development and poverty, b) non-communicable disease, and c) injuries, HIV/AIDS was found to be a fourth major contributor (Bradshaw *et al*., 2003). The presence of these four types of disease among the 10 leading causes of death in the population indicates that society is bearing both an extensive and diversified burden of disease. In turn, such a burden of disease implies an extensive and diversified need for care.

While the National Burden of Disease Study (Bradshaw *et al*., 2003) focuses on causes of death, it is also important to consider the care impact of those diseases that generally cause substantial morbidity, but relatively little mortality. Degenerative conditions in adults, such as nervous system disorders (e.g. multiple sclerosis or Alzheimer’s disease) and mental disorders (e.g. schizophrenia or bipolar depression), as well as debilitating conditions in children such as severe instances of spina bifida, contribute considerably to the disease burden, although limitedly to the mortality burden. The magnitude of mental health problems has been projected to increase through population ageing, specifically because of the increasing life expectancy of people with mental disorders, and the growing number of people reaching older ages at which the risk of neurological disorders such as Alzheimer’s and Parkinson’s disease is increased (WHO, 1998; National Institutes of Health, 2003).

The gravity of the estimated demographic and epidemiological impacts of the ongoing HIV/AIDS epidemic warrants separate mention. In 2000, AIDS was the leading single cause of death in the country, accounting for an estimated 30% of all deaths (Bradshaw *et al.*, 2003). Projections to 2010 indicate that, in the absence of wide availability and use of interventions that reduce HIV/AIDS mortality and morbidity, the already large burden from HIV/AIDS is expected to grow rapidly over the next 10 years[3]. Moreover, it is projected that the disease burden from HIV/AIDS does not diminish the burden from other causes (Bradshaw *et al*, 2003). Treatment of and caring for people with AIDS in the formal sector is complicated by the particular manifestations and progression of AIDS which often do not fit into conventionally-employed curative, chronic or palliative care models (UNAIDS, 2000a: 2-3; Oleske & Czarniecki, 1999: 1287; Cox, 1998: 22), hence contributing extensively to the need for informal care.

1.2.1.3 Health sector change

While South Africa's extensive burden of disease imply a particularly large demand for care, existing formal health services in the public sector fall short of providing adequate and satisfactory care to those in need of care (Uys & Hensher, 2002; Lee & Zwi, 1997; Ministry of Welfare and Population Development (MWPD), 1997; Njongwe, 2003). Reasons here for include under-staffing, unmanageable workload, limited physical space (Leon *et al*., 2002); overcrowding, long waiting times, limited service hours (Modiba *et al*., 2002); inadequately and inappropriately trained health workers, changed requirements in primary health care service delivery, shortages of equipment (Ijumba, 2003); the exodus of health workers from the public sector, increased rates of absenteeism of health workers, and an increased patient load related to HIV/AIDS (Lehmann & Sanders, 2003; Bateman, 2001); lack of adequate support systems and dwindling public sector funding (Njongwe, 2003).

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[3] It is acknowledged that a national task team has been appointed by the Minister of Health during August 2003 to co-ordinate the drafting of an operational plan for a countrywide anti-retroviral treatment programme. It is also acknowledged that the treatment programme is not rolling out according to plan.

The de-institutionalization policies of the government in relation to ageing, HIV/AIDS, and physical and mental disability, have led to promoting a shift from institutional care to community and home care with the family as the core support system (Department of Health, 2001; Department of Health, 1997; Lee & Zwi, 1997: 157; McLaren & Philpott, 1997: 186; MWPD, 1997).

Moreover, in terms of financing of the public health sector, 1998/99 data indicated decreasing per capita financing of health care by the government, and it is unlikely that this decrease was temporary as it is associated with major policy changes that affect the long-term climate for public health care financing in South Africa (Doherty *et al*., 2003).

While there seems to be less shortcomings in the private sector, private care falls beyond the financial capability of the majority of the population (MWPD, 1997; Whiteford *et al*., 1995), and it is estimated that less than 20% of the population made regular use of private sector services in 1998/99 (Cornell *et al*., 2001). Although private health care usually is presumed to be affordable to those who have access to medical schemes, only 16% of the population could afford this sort of private cover in 1998/99 (Cornell *et al*., 2001).

On the one hand, demographic and epidemiological changes have led to an increased demand for care. On the other hand, health system changes, shortages in formal health care delivery, and the spiralling costs of private care, have led to decreased availability of formal care, or at least more difficulty in accessing formal care. This gives reason to believe that many frail, sick and disabled people have no choice but to increasingly rely on informal care offered at home or elsewhere in the community.

1.3 Rationale for the study

In much of the industrialized world, informal carers are recognized as a valuable, essential resource in society. This recognition, and actions taken to support them, are largely based on research conducted among informal carers in those countries. However, in South Africa, it is not clear how reliant the population is on such care; who it is that takes on the role of an informal carer in families; and what the characteristics are of those who shoulder this burden. A literature search has revealed that research on informal care has received very little attention in South Africa. A study was commissioned during 1999 by Age-in-Action, and valuable information was collected about a sample of carers and their carer experiences in eight provinces (Joubert *et al*., 2002). However, no publications assessing the national extent of informal care were found, neither any other study that collected nationally-representative data of carers' characteristics. If this resource is to be relied upon by government, families and individuals in future—as implied above—there is a need to address the lack of research-based knowledge about them.

Furthermore, various international fora recognize the importance of informal care worldwide, as well as the need to use research-based findings in developing policy and interventions, and have encouraged and recommended research about informal carers (cf. United Nations Expert Group on Caregiving and Older Persons (United Nations, 1997); World Health Organization, 1999a; World Health Organization and the Milbank Memorial Fund, 2000; United Nations, 2002b;

United Nations Development Fund for Women (UNIFEM), cited in Budlender, 2002).

1.4 Research questions

Against the background given above, three broad research questions were identified. The first seeks to answer what the prevalence of informal care in the country is. The second question concerns the demographic and socio-economic characteristics of informal carers, while the third concerns gender and age differentials in the likelihood of being an informal carer.

1.5 Purpose, aim and objectives

The purpose of the study is to contribute to the limited research on informal carers in South Africa. It is hoped that the findings will enhance recognition and support of this essential health care system resource in the country, and that it will encourage further, comprehensive research about informal carers.

The study aims to establish the prevalence of informal care in South Africa, and to present a demographic and socio-economic profile of people involved with such care.

The following objectives are pursued:

(a) to establish the proportion of the adult population who are informal carers;

(b) to describe selected demographic and socio-economic characteristics of these carers;

(c) to describe carers’ access to assistive household amenities in the place of care;

(d) to examine the prevalence of informal care in the adult population by selected demographic and socio-economic characteristics; and

(e) to investigate gender and age differentials in relation to the likelihood of being an informal carer.

Chapter 2

Literature Review: Caregiving

2.1 INTRODUCTION

Research on caregiving in the developed world is well-established and extensive, and a decade ago it was stated that the literature was so voluminous that it was "virtually impossible to contain within a coherent scheme of understanding" (Gubrium, 1995: 267). In the early 1960s, a watershed event in the United States of America (US)—a major conference on the three-generational family—acknowledged not only the continued and important informal caregiving role of family members to older persons, but also recognized that the effects of such caregiving on the carers were hardly touched upon (Brody, 1995: 15). In the 1960s then, some studies were conducted about these effects in the US, while the first large-scale studies were conducted in the United Kingdom. Studies on the subject increased considerably hereafter through the 1970s, developing into a major stream of research in the 1980s (Brody, 1995: 15). This was confirmed by Wullschleger, Lund, Caserta & Wright (1996) who were of the opinion that over that past decade, caregiving, in particular the burden of caregiving—has been one of the most researched topics in gerontology in the United States.

Given the purpose of the thesis study, i.e. to contribute to the limited research on informal care in the home setting to persons with a long-term care needs, it was necessary to refine the literature review from the broad concept "caregiving" to what would best suit the objectives of the study. Chapter 1 states that it is not within the scope of the thesis to describe the wide-ranging meaning of 'care', but to focus on that meaning of 'care' that relates to the task of attending to another person in the context of human frailty, disability or ill-health. To optimally enlighten the subject matter of the thesis, this chapter hence primarily focuses on three caregiving concepts, i.e. 'long-term care', 'home care', and 'informal care' as sketched in Figure 1.1. The discussion of these concepts seldom are mutually-exclusive, and in this chapter it is inevitable that aspects of, for example, informal care and home care will be dealt with in the section on long-term care, and vice versa.

2.2 LONG-TERM CARE

Demographic and epidemiological changes have resulted in changes in the health needs of most of the world's nations, and long-term care services have become essential to the health and well-being of persons with chronic disease, frailty and disability (WHO, 2002b: vii, 1; Brodsky *et al*, 2003: iii). Longer life expectancy and the associated increase of chronic disease were important factors in establishing the concept 'long-term care' as part of the lexicon. With almost all countries of the world now experiencing population ageing, many more older persons than ever before are suffering from both acute and chronic disabling conditions, and much of the demand for long-term care emanates from the needs of the older population. However, demands by younger segments of the population are also large and growing. Sources of such additional pressure include the HIV/AIDS epidemic with its associated health needs among young children and those in their young- and middle-adult ages; changes in dietary habits and lifestyle that contribute to a rise in cardiovascular disease, stroke and diabetes in adults; and economic development that tend to increase chronic-debilitating injuries related to motor vehicles, industrial accidents and toxic chemicals across ages (WHO, 2002b: 1; Mosley *et al*, 1993: 678).

A wealth of literature on 'long-term care', 'home care' and 'informal care'—both as separate concepts, and combined into the concept of 'long-term informal care at home'—is available from the developed world. Long-term care is broadly defined by Kane (2003: 80) as a "social service directed at persons with severe chronic health problems". A WHO definition referring to both care recipients and different types of caregivers, states that long-term care "includes activities undertaken for persons that are not fully capable of self-care on a long-term basis, by informal caregivers (family and friends), by formal caregivers, including professionals and para-professionals (health, social and others), and by traditional caregivers and volunteers" (WHO, 2002d: 7). A similar definition is provided by Kodner (2003: 91-92), acknowledging both health and social needs in long-term care: "…long-term care is part health care and part social service. It encompasses a broad array of primarily low-tech services provided by paid professionals and para-professionals—as well as unpaid family members and other informal helpers—to individuals with chronic, disabling conditions who need help on a prolonged basis with daily activities of living".

These definitions show that long-term care refers to a wide range of supportive services and assistance to persons who, because of chronic illness, disability or frailty, are not able to function independently on a daily basis. They further indicate that the need for long-term care does not necessarily correspond to medical conditions, but also to problems with performing ADLs such as eating, bathing, dressing, toileting and transferring, and IADLs such as shopping, house cleaning, meal preparation, and managing financial issues (Hooyman & Kiyak, 2002: 539, 103). The provision of assistive devices such as canes and walking frames, and doing home modifications, e.g. by fitting hand rails and ramps, or installing emergency alert systems, add to the range of services and assistance in long-term care (Feder, Komisar & Niefeld, 2000, cited by Kodner, 2003: 91; WHO, 2002d: 7).

Long-term care refers thus to services with the aim of minimizing, rehabilitating, or compensating for the loss of independent physical, cognitive, and/or mental functioning, and can be delivered in the home, community or institutional settings (Hooyman & Kiyak, 2002: 539; Kodner, 2003: 92; WHO, 2002b: 3; WHO, 2002d: 7). Kane *et al*., 1998, cited in Hooyman & Kiyak (2002: 539), summarise the nature of long-term care by stating that it aims to integrate health care treatment and assistance with daily life tasks, while addressing social, environmental and medical needs over a prolonged period.

A growing need for long-term care policies generally is associated with the developed world where there is an ongoing debate about who is responsible for long-term care. While the debate continues whether the individual, the family or governments should be responsible for providing for persons in need of long-term care, systems of long-term care have been developed by many governmental, non-governmental and private organizations, often differing among societies. Countries that have recognized the need for formal and public support in the caregiving situation, have introduced a range of initiatives, which include providing information and training to carers, offering respite care, providing tax benefits, giving cash payments, ensuring pension credits to carers who need to sacrifice their formal employment, and providing purpose-built or service-enriched housing.

On the other hand, a limited number of developing countries have developed policies, services or benefits to support such care, while it is reported that long-term care needs are increasing in the developing world at a rate that far exceeds that experienced by industrialized countries (WHO, 2002b: vii, 1; Brodsky *et al*, 2003: iii). Table 2.1 below, quoted from a technical report of the WHO-Study Group on Long-term Home-based Care (WHO, 2000a), provides a summary outline of likely differences in the development of home care services.

Table 2.1: Patterns of development of home-based long-term care services at different stages of economic development

Lowest-income economies	Low-income economies	Middle-income economies	High-income economies

Lowest-income economies	**Low-income economies**	**Middle-income economies**	**High-income economies**
Almost all care is informal	Almost all care is informal	More limited informal care	More pressure on availability of informal care
Direct care is informal	Paid local community workers	Paid local community workers	Few community health workers
Large voluntary community workers (payment in kind, some training)	More training of these workers	Some personal care and home-making, and less clinical care	Specialized personal care and home-making workers with no clinical or community development roles
No personal care or home-making, but counselling, simple clinical responsibilities, and dispensing of supplies	No personal care or home-making, but counselling, simple clinical responsibilities, and dispensing of supplies	Professional staff involved in more direct home care	Varying professional training for these workers and concern for over professionalisation
Also community development role	Also community development role	Emergence of some social-system-based home care	Professional home care highly developed
Professional staff in a supervisory role	Professional staff in a supervisory role	Growing institutional care	Institutional care of major importance
			Segregated social- and health-based home-care systems

Source: WHO, 2000a: 20.

A few country examples are given below, mainly from the developed world (Germany, Italy, Japan, Spain and Sweden), but including two African examples too (Uganda and South Africa). The examples mainly refer to long-term care in the context of demographic ageing, which—especially so in developed regions, but also emerging in developing regions—continue to be an important concern in the area of caregiving in view of the associated changes in the epidemiological and health systems profiles of a population. Examples from the first six countries are rather short, but more detail is given when referring to long-term care in South Africa. Additional to the ageing/older person context in the South Africa example, reference is also made to long-term care needs of persons with AIDS-related disease, mental illness and physical disabilities.

2.2.1 Germany

In the year 2000, average life expectancy at birth in Germany was estimated at 77.4 years, the total fertility rate (TFR) 1.4 births per women, the median age 40 years, and the country had an ageing index of 103 persons aged 65 or older per 100 children 0 - 14 years. The latter is projected to increase to 187:100 in 2030. These indicators are pointing to a nation experiencing advanced demographic ageing, and in 2000, 16.2% of the population was 65 years or older (Kinsella & Velkoff, 2001).

In 1994, through enactment of legislation creating a universal social insurance programme to cover long-term care, Germany has introduced a mandatory insurance scheme for such care, known as Soziale Pflegeversicherung or Social Dependency Insurance. This programme is financed by premiums from employers, employees and pensioners. About 90% of the population are covered by a public insurance scheme and the remainder by a funded private insurance scheme.

The public scheme involves three dependency levels that determine the level of benefits, and according to national eligibility criteria, an individual is entitled to choose between different types of services or cash benefits. In order to qualify for long-term care benefits, a person must require help with at least two ADLs, for more than 90 minutes a day, over a period of six months. Beneficiaries can receive home care benefits in the form of in-kind services, cash, or a combination of both. Persons with levels of dependency lower than the minimum criteria are not covered by the insurance, and rely on privately-purchased formal care, or informal care by relatives or friends (Comas-Hererra *et al.*, 2003: 4; Kodner, 2003: 105; Lechner & Neal, 1999, cited in Curry, 2003a: 17).

2.2.2 Italy

In 2000, Italy's average life expectancy at birth was estimated at 79 years and its TFR at 1.2. The median age was 40 years, and by 2030, the population is projected to have the highest median age globally with half its population aged 52 or older. The ageing index in 2000 was 127, expected to rise to 261 in 2030. Italy recently became demographically the oldest of the world's major nations with 18.1% of its population 65 years or over (Kinsella & Velkoff, 2001).

Three main sources of assistance are responsible for Italy's public long-term elder care needs, i.e. community care, institutional care and cash allowances. Health services provided within the Italian National Health Service are free of charge to older persons, being mainly financed by national and local taxation. A notable feature is the non-means-tested cash benefits for long-term care, which may explain the country's strong reliance on private home-based care purchased by those who require care (Comas-Hererra *et al*, 2003: 4).

2.2.3 Japan

Japan was estimated to have the highest average life expectancy at birth in 2000, i.e. 80.7 years, a TFR of 1.4 births per woman, a median age of 41 years, and 17% of its total population were 65 years or older. Japan had an ageing index of 115 in 2000, projected to increase to 231 in 2030. Of the population 65 or older, 22% were 80 years or older (Kinsella & Velkoff, 2001).

In 2000, about 90% of the primary carers in long-term care in Japan were family members. However, the particular longevity and fertility situation of the society, combined with familial changes, present challenges to meet the needs of the growing number of older persons in need of long-term care. The Japanese Government started to implement its Long-term Care Insurance Programme in April 2000, and a large number of older persons and informal carers have started making use of formal care services such as home-helper services, day care, and respite services offered by the programme to supplement their tasks. However, informal carers are still providing the majority of care to older persons in need of long-term care (Shibata & Yamada, 2003: 12-13).

2.2.4 Spain

In 2000, the proportion of the population 65 years or older, was 16.9%, making Spain one of the five demographically-oldest countries in the world (Kinsella & Velkoff, 2001). Average life expectancy at birth in mid-2003 was estimated at 79 and the TFR at 1.2 (Population Reference Bureau, 2003).

For its long-term care needs, Spain relies greatly on informal care, but as female labour force participation increases, it is expected that the country will increasingly rely on formal care. Currently, access to publicly-funded long-term care is based on an assessment of needs and resources, but services are tightly rationed because of low levels of supply. Health care services within the National Health Service are free of charge to older persons, but social care services are means-tested. Formal long-term care is financed mainly trough taxes and, to a lesser extent, charges and co-payments (Comas-Hererra *et al*, 2003: 4).

2.2.5 Sweden

Average life expectancy at birth in Sweden was estimated at 79.6 years in 2000, and the country's TFR at 1.5. Just over 17% of the population was 65 years or older, and the country had an ageing index of 94, which is projected to rise to 169 in 2030 (Kinsella & Velkoff, 2001).

Sweden has a strong commitment to publicly-funded and publicly-delivered health and social services of citizens of all ages. A central tenet of the Swedish welfare state is that older persons are guaranteed social services, adequate housing and health care according to their needs (Zappolo & Sundström, 1989, cited in Kodner, 2003: 120; Johansson, 2001, cited in Kodner, 2003:120).

Older persons could demand, by law, to be cared for by their children until 1956. In 1982, the Swedish Social Services Act established the legal right of an individual to assistance from society. In 1997, over 94% of care to older persons was provided by the state. Through the country's Paid Caregiver Programme, the government are paying informal carers a salary which is determined by the older person's care needs and the number of hours deemed necessary to provide the required care. Additionally, carers receive benefits of social insurance, as well as the pension credits they would have received in regular employment. Employed informal carers are furthermore entitled to 60 days paid time off from the workplace to care for older family members (Lechner & Neal, 1999, cited by Curry, 2003b: 2).

2.2.6 Uganda

In mid-2003, average life expectancy at birth in Uganda was estimated to be 44 years, the TFR 6.9, and 2% of the total population were estimated to be 65 years or older (Population Reference Bureau, 2003). Although a small proportion of the population currently are older persons, the older population is expected to grow significantly during this century (Lechner & Neal, 1999, cited by Curry, 2003b: 2).

Uganda has no formal government care services for older persons who require care, and relatives or other community members usually assume responsibility for their care. Although older people usually are regarded with respect, increasing numbers of adult and young Ugandans move to urban areas in search of employment, contributing to the erosion of traditional customs, including physical and material care for older persons. Although Uganda has a National Social Security Fund, neither home care services for older persons, nor nursing home services are covered in the fund. Instead, the Church of Uganda is one of the institutions that has established services for older persons, offering residential care to destitute older persons who have no family to care for them (Lechner & Neal, 1999, cited by Curry, 2003b: 2).

2.2.7 South Africa

The average life expectancy at birth in South Africa was estimated to be 61 years in 1990 (Bradshaw *et al*., 2003), but according to the modelling work of the Actuarial Society of South Africa, it was estimated to be shortened to 51 in 2004 (Dorrington *et al*, 2004), largely as a result of AIDS mortality over the past decade.

Despite shortened life expectancy, the population is ageing and will continue ageing over the next 10 to 15 years (Haldenwang, 2001; Joubert *et al*., 2003) The country accommodated 3.28 million older persons (60 years or older) during the 2001 population census, accounting for 7.3% of the total population (Statistics South Africa, 2003). These figures make the South African population one of the demographically-oldest populations on the continent. It is projected that by 2015 both the proportion and number of older people will increase to 8.8% and 4.25 million respectively (ASSA, 2004).[1]

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[1] These figures were calculated taken into account the estimated impact of HIV/AIDS as modelled by the Actuarial Society of South Africa (ASSA), using the ASSA2002 model. This demographic model of ASSA uses a wide range of empirical evidence from different sources to provide estimates of the numbers of people directly affected by HIV and AIDS. A change scenario has been used with specific intervention assumptions in respect of information and education campaigns, improved treatment of sexually transmitted diseases, voluntary counselling and testing, mother-to-child-transmission prevention, and antiretroviral treatment. Downloaded on 23 July 2004 from http://www.assa.org.za/

In 2001, South Africa had an ageing index of 23, which is projected to raise to 30 in 2015 (ASSA, 2004). These recent projections confirm the earlier work of Haldenwang (2001) and Joubert *et al*. (2003) by continuing to show that, despite the demographic impact of HIV/AIDS, South Africa's population will continue ageing in at least the short to medium-term future. Moreover, the 2000 estimates in the South African National Burden of Disease Study show that non-communicable disease accounted for 84% of the causes of death in older persons, with cardiovascular disease and malignant neoplasms accounting for the great majority of chronic-disease deaths. These findings highlight the already-existing long-term care needs, and the expectation that the need for long-term care services associated with elder care will increase.

2.2.7.1 Long-term care services to older persons

Despite South Africa having one of the oldest populations in Africa and despite the considerable burden of chronic disease, there is currently no formal long-term care insurance scheme available with an exclusive interest in long-term care in the country, while governmental support is available only to those older persons who have been classified with a severe degree of frailty. Prior to the current government's health and welfare reform, financial support via state subsidies was available to institutions that accommodated and cared for older persons. However, the 1997 White Paper for Social Welfare (MWPD, 1997) referred to an inappropriate emphasis on the Government's responsibility for the care of older persons. In its approach to ageing, the document proposed a shift from institutional care to community-based care and support services, which was followed by the implementation of a new, fundamentally-diminished subsidisation formula for residential elder care. Current welfare policy states that only older persons with a specified advanced degree of frailty would be accommodated in state-supported institutions, implying that less frail older persons who need care or help in their day-to-day living, need to look after themselves or should be cared for by relatives or community members. The White Paper states that family care will be the baseline of all age management programmes, that home care for older persons will be encouraged; and that community-based services within the family as the core support system, should be the foundation of a new dispensation on ageing (MWPD, 1997). On the other hand, the 1998 White Paper on Population Policy states that there is a growing need for residential care for older persons which is not being met (MWPD, 1998), an issue confirmed in needs assessment studies conducted qualitatively among older persons in three provinces (Joubert *et al.*, 1998a & b; Swart *et al.*, 1998) and by the research of Chinkanda (1989).

It is suspected that the majority of older South Africans may have particular long-term care needs, which in part have been created and/or enhanced because of certain macro political and health system decisions, and that they may be unfavourably affected by the scarcity of affordable formal long-term care services. Grounds for suspecting this include that the great majority of today's older persons were exposed to institutionalised inequalities and disadvantaged contexts during the 45 years of apartheid policies, limiting the chances for healthy ageing in many of them (Ferreira, 1998). Then, after being rid of institutional discrimination and disadvantage, low priority currently is given to the older population in health and other social transformation programmes. Additionally, reduced availability of *in*formal long-term care is suspected in the light of diminished support from younger generations, and financial inability to purchase private long-term care services is indicated in the majority of the country's older persons. Compare the following findings from different studies, supporting these reasons:

- A report on poverty and older persons found that 30% of persons 50 years or older lived in households earning less than R800.00 per month, and a further quarter lived in households earning less than R400.00 per month (May, 2003);
- The 1998 Demographic and Health Survey found that only 13% of persons 65+ reported having access to a medical aid, while about half of the population 65+ were taking two or three prescribed, listed drugs for chronic conditions (Department of Health, Medical Research Council & Measure DHS+, 2002);
- While there were over 3.28 million persons 60 years or older, a government report informed in 2002 that only three geriatric departments existed in the country, while only one was operational (Department of Social Development, 2002a: 29);
- Research studies have found that older persons' health care needs and concerns are overshadowed by the current emphasis on child, adolescent, maternal and reproductive health care (Charlton, 1996; Kinsella & Ferreira, 1997; Charlton, 1998; Ferreira, 1998; Joubert & Bradshaw, 2004);
- Several studies refer to dissatisfaction among older persons with the situation in public health care services, including complaints about client overloads, understaffed facilities, shortages of medication, unavailability of assistive devices, inefficient appointment systems, long waiting times, and unacceptable treatment by health personnel (Ferreira & Charlton, 1996; Ferreira, Charlton & Mosaval, 1998; Joubert *et al.*, 1998a, 1998b; Swart, *et al.*, 1998);
- Although found to have many positive attributes, including alleviation of poverty in

general, and reducing household vulnerability, the Older Persons Grant has lost value through the years due to inflation. It is well-documented that grant-sharing is the norm in older South Africans, implying that the grant is often not for individual use, but that it gets rerouted for familial or household needs (Department of Social Development, 2001; Department of Social Development, 2002a; Devereux, 2002; Institute of Development and Policy Management (IDPM) & HelpAge International, 2003; Møller & Sotshongaye, 1996); and

- In the past, many of the country's older persons relied upon financial and in-kind assistance from their offspring to manage health care and other costs of living. Caregiving to sick, disabled or frail older persons were often expected from older persons' daughters or daughters-in-law (Joubert *et al.*, 1998a, 1998b). It is suspected that such care and support are not as readily available as before due to, among other, declines in fertility (Moultrie & Timæus, 2002), AIDS-related increased mortality among young adults (Dorrington *et al.*, 2002), and greater female participation in the labour force (Casale & Posel, 2002).

2.2.7.2 Long-term care services to persons with mental and physical disabilities

Until the 1970s, the government was prohibited by law from operating community-based mental health services, and as such, supported the operation of residential institutions that provided custodial care for persons with chronic mental illness and retardation (AAAS & PHR, 1998). Considerable state subsidies or reimbursements were available to such institutions, and for those that accommodated persons with physical disabilities. The 1997 Welfare White Paper advocates the development of home-based, family-oriented and community mental care strategies (MWPD, 1997), a direction endorsed by the White Paper for the Transformation of the Health System in South Africa promoting community-based mental health services that is integrated with other health services (Department of Health, 1997), and promoted by Lee and Zwi (1997: 157) who perceive de-institutionalisation and community-based care as critical elements of mental health services. The importance of family involvement in the care and rehabilitation of persons with physical disabilities is emphasised by the Intersectoral Rehabilitation Policy Document, while one of the agreed-upon priorities of the Departmental Committee on Developmental Social Services refers to the promotion of community-based care for the disabled (Department of Welfare, 1997: 11, 21). This is supported by McLaren and Philpott (1997: 186) who perceive the promotion of community-based rehabilitation for disabled people as a key area where progress should be made.

Similar to the situation regarding long-term care services for older persons, home and community care services are promoted in the field of mental and physical disability, but state resources are limited to assist, support or train home- and community carers, or to assist care recipients with caregiving tasks in the community or at home through trained home- or community care professionals. In 1998, for example, it was reported that 90% of state funds remained committed to mental health institutions, and although some NGOs have established community-based programmes, they are few in number (AAAS & PHR, 1998).

2.2.7.3 Long-term care services to persons with AIDS-related illnesses

The AIDS epidemic adds a major challenge to meeting the long-term care needs of the population. Over 5 million persons, or 11% of the total population, were estimated to be

HIV-infected in 2004, while 19500 persons or 3.9% of the estimated 500 000 in need of treatment, were receiving anti-retroviral therapy in the public sector (Dorrington *et al*., 2004: iii).

Research has shown that the need for care for HIV/AIDS-related illness has intensified over the past five to seven years at various levels of care provision—from informal care at home by family members, organized home care by professionals and volunteers, clinic care, hospice care, to hospital care (Johnson *et al*., 2003; Shisana *et al*., 2003; Steinberg *et al*., 2002). Although an increase has been experienced in the formal care sector, the perplexing manifestations and progression of the disease often do not fit into the conventional curative, chronic or palliative care models of the formal sector (Cox, 1998; Morrison, 1993; Akintola, 2004), and hence have intensified the demand for informal care in the home-setting.

In 1997, the White Paper for Social Welfare (MWPD, 1997) stated that home-based, family-oriented and community care strategies are the preferred options for coping with the need for care and the psycho-social consequences of HIV/AIDS. Further to this policy statement, the Department of Health more recently has issued its National Guideline on Home/Community-based Care (Department of Health, 2001); the development of home and community-based care has been advanced through government funds that have been made available to the Department of Health and the Department of Social Development (Government Communication and Information System, 2004); and the training of community carers, and the provision of home-based care kits to community carers have been included in the official strategies to improve HIV/AIDS care and reduce the burden on the formal system (Department of Health, 2004).

Given the protracted nature of AIDS-disease, combined with the huge number of AIDS-sick persons, a vast caregiving task has been placed on the shoulders of informal carers in the home-setting. Older persons, in particular, may suffer a unique burden as a result of the AIDS epidemic. While they are largely overlooked in the context of the epidemic, research in Thailand, Uganda and Zimbabwe have shown that older persons are commonly involved with the living and caregiving arrangements of persons with AIDS (Knodel *et al.*, 2000; Knodel & Saengtienchai, 2001; Ntozi & Nakayiwa, 1999; WHO, 2002f). Although a common phenomenon in South Africa that many older persons, particularly those in multi-generational households, assist in raising their grandchildren, including caring for sick and disabled ones (Gillis, 1992: 23; Joubert *et al.*, 1998a, 1998b; Møller & Sotshongaye, 1996), the AIDS epidemic has brought added responsibility to many of the country's affected older persons who are often left with little choice but to look after and support their children, grandchildren and other relatives infected or affected by the epidemic (Department of Social Development, 2002a; Department of Social Development, 2003; Ferreira *et al.*, 2001; Ferreira & Brodrick, 2001; Johnson *et al.*, 2003).

The AIDS epidemic has the potential to affect older persons' health and well-being in various direct and indirect ways, among other through physical and mental stress, anxiety and burnout from caregiving strains and a greater burden of household work; HIV infection through hands-on caregiving activities; as well as financial demands on older carers' income or savings related to the health care costs of their sick off-spring; the provision of material support to their AIDS-ill children and their dependants; funeral costs; and suffering the loss of current and future financial support which the ill child or deceased would have provided (Knodel & VanLandingham, 2000; Legido-Quigley, 2003; WHO, 2002f). These conditions and situation, in turn, have the potential to increase older persons' risk of needing long-term care themselves.

2.2.7.4 Support in long-term care needs

It can be argued that Government makes a direct financial contribution to long-term care needs through three particular social grants, i.e. the Grant-in-Aid, the Disability Grant and the Care Dependency Grant. The Grant-in-Aid is payable to someone who is taking care of a person in need of full-time attention and who is a recipient of a grant, thereby contributing towards enabling incapacitated persons to obtain the assistance of a carer. The Disability Grant is paid to persons 18 years or older, who have been disabled for six months, or longer, while the Care Dependency Grant is available for children, between the ages of 1 and 18, who requires and receives special care at home due to severe mental or physical disability (Department of Social Development, 2002a; Department of Social Development, 2002b).

Three more social grants are available which indirectly may contribute to assist persons with long-term care needs. The means-tested Child Support Grant is payable to a primary caregiver who takes care of the daily needs of a child or children (maximum six children), from birth to its 14th birthday, in urban households with a monthly income less than R800.00, or households in rural areas and informal settlement with a monthly income less than R1 100.00. Foster parents can receive a Foster Care Grant in respect of children who have been placed in their care through a court order. The Older Persons Grant, a non-contributory grant that is means-tested for income, is payable to women 60 years or older and men 65 years or older (Department of Social Development, 2002a; Department of Social Development, 2002b). However, the potential benefits of these grants related to long-term care have yet not been established.

There are also a number of NGOs that provide services such as training, psycho-social counselling, and transport to facilitate or support long-term informal care at home. These organizations include Age-in-Action, the Cancer Association of South Africa, various affiliations of the Hospice and Palliative Care Association of South Africa, and a range of community- and faith-based organizations. Additionally, generous donations from humanitarian organisations have facilitated various services in support of long-term informal caregiving. These services are being referred to in the next section.

2.3 HOME CARE

Some aspects of home care have inevitably been dealt with while discussing long-term care in the previous section. Although home care may be offered for shorter periods of time, this section primarily focuses on home care as a *long*-term responsibility. The term ‘home care’ is being used in the thesis, but it is acknowledged that the terminology may differ among countries, providers and users of such care. Terms such as ‘home-based care’, ‘community home-based care’ and ‘family care’ were encountered in the literature, but the underlying meaning mostly was interchangeable with the meaning of ‘home care’ as defined below. It is acknowledged that home care may be combined with (temporary) care in other settings too, such as respite care in a formal care facility like a hospice’s in-patient unit, or periodic care offered in a day care centre, but home care in this thesis focuses on care provided in the *home setting*.

A variety of definitions of home care were found, but in general, the concept refers to the provision of health and related care by one person to another in the home setting. In one of its publications on caregiving, the WHO (1999b: ix) defined home care as “the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person’s maximum level of comfort, function and health including care towards a dignified death”. In this publication, the WHO classified home care services into preventive-promotive, therapeutic, rehabilitative, long-term maintenance and palliative care categories.

In terms of the requirements, resources, rationale, goals and elements of home care, as well as training and specialization in home care, vast differences exist between regions, countries and communities at different stages of economic development. In resource-limited settings, one of the important requirements for home care is to ensure the provision of the basic needs of shelter, food, clothing, safe water, sanitation, fuel, heat and cooking utensils (WHO, 2002e), while satisfying these needs mostly is a given in resource-rich settings.

An example of differences in home care is sketched below by providing information on selected home care programmes and services in Canada, Botswana and South Africa. Canada is perceived as housing a largely wealthy and resource-rich society, while, in comparison, Botswana and South Africa are housing largely low- to middle-income and resource-limited societies. These differences may contribute to the differences in goals and elements of home care as outlined below.

2.3.1 Canada[2]

In Canada, home care has been broadly defined as “an array of services which enable clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives”. The Health Canada report (1990: 1) quoting this definition, further described definitional aspects of home care as it applies to Canada, stating that home care is delivered under numerous organizational structures, and similarly numerous funding and client payment mechanisms. Home care may address needs specifically associated with a medical diagnosis, and/or may address functional deficits in ADLs. While home care is generally perceived as a health program—with health broadly defined—it may have to provide services which in other contexts might be defined as social or educational services in order to be effective (Health Canada, 1990: 1,2).

The target audience for receiving home care is a wide one. Home care may be appropriate for people with minor health problems or disabilities, as well as for those who are acutely ill and who require intensive services and sophisticated equipment. There are no upper or lower limits on the age at which home care may be required, although as in other segments of the health system, utilization tends to increase with age (Health Canada, 1990: 3).

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[2] The examples of home care offered here are not an exhaustive list of the services per country, but are examples of services found in the literature available.

The comprehensive, widely-available and well-resourced character of home care in Canada is reflected in another report prepared by the Canadian Home Care Association (1998), stating that all Canada's provinces and territories have developed definitions of home care specific to their particular home care programmes. Due to the diversity in range and orientation of services among home care programmes, it is possible that one, when referring to programmes in his/her respective provinces and territories, could refer to different sets of services and clients. For example, home care programmes, characterized by an acute care orientation are defined differently from those incorporating a broader range of services including post-acute, long-term health care and home support services, into one programme. Programmes offering the latter services are, for example, established in Saskatchewan, Manitoba, Quebec and Prince Edward Island. In New Brunswick, again, two programmes are operational, i.e. the Extra-Mural Program offering both short- and long-term home care with an emphasis on health services, and the separate Long Term Care Program that emphasizes both long-term home support and long-term residential care services (Canadian Home Care Association, 1998: 1).

A combined health and social support services orientation is generally included in home care delivery in Canada. With local hospital reforms such as consolidation, single-day surgery, and general shorter lengths of hospital stays, the need for the provision of heavier acute care in the home has increased and has been taken up by home care programmes. Although it hence may appear that hospital substitution or post-acute services have taken on greater emphasis relative to maintenance and prevention services than was the case in the past, acute home care is still regarded as only one of several components of home care services. Diverse clients with diverse needs still have diverse access to health care, personal care, homemaking and other social support services in the home setting to accommodate their needs, as well as those of their family and volunteer caregivers (Canadian Home Care Association, 1998: 1).

2.3.2 Botswana

In Botswana, a home care programme called the Community Home-based Care Programme, is in existence since the early 1990s (Mathebula, 2000). The programme was initiated by the government of Botswana in response to the country's particularly high prevalence rate of HIV infection and the strain of HIV- and AIDS-related disease on the health care system which by 1999 had 65% of all hospital beds throughout the country occupied by persons with HIV/AIDS (WHO, 2000c; Motsa, 1999).

In this Botswana example, community home-based care is defined as "...care given to individuals in their own natural environment, which is their home, by their families, supported by skilled welfare officers and communities to meet spiritual, material and psycho-social needs, with the individual playing a crucial role". The target group for the programme is, on the one hand, any person with HIV-related diseases or AIDS, and all other chronically-ill patients, and on the other hand, social welfare officers who include social workers, district health officers, nurses, nutrition officers, and other allied health professionals (Botswana National AIDS Control Programme (NACP) 30, 1996 as cited in WHO, 2000c: 9).

The rationale for the implementation of the programme in Botswana includes that home care is perceived as the best method to care for large numbers of people with terminal illnesses for the following reasons: “a) the extended family is traditionally the caring unit in Botswana society; b) patients prefer to die at home; c) inadequacy of institutional health services to fully manage the AIDS epidemic; d) sharing the challenge between hospitals, district health services, families and the community; and e) the family is seen as a target for AIDS prevention”. In addition, it was argued that a caring family will reduce the risk of ostracising people with HIV/AIDS (NACP 30, 1996 as cited in WHO, 2000c: 9).

The goal of the programme is to prevent HIV transmission and to reduce the impact associated with HIV/AIDS on those infected and affected by the disease. Specific objectives include to ensure optimum levels of care for terminally ill patients; to avoid the ‘dumping syndrome’; to avoid unnecessary hospital admission; to provide nursing care in the home setting; to provide an on-going counselling service to both persons with AIDS and their families; and to refer terminally-ill patients to social, welfare and other appropriate agencies for material support (NACP 30, 1996 as cited in WHO, 2000c: 9).

2.3.3 South Africa

In South Africa, similar to the case in Botswana, the AIDS epidemic was an important contributing factor in the development of home care services (compare paragraph 2.2.7.3). However, services are not restricted to AIDS-related care only, but are also offered to persons with other conditions such as frailty in older people, physically- or otherwise abused older people, or people with debilitating cancers.

Providers of home care, either actively doing so or being instrumental by facilitating it, include Age-in-Action, the Cancer Association of South Africa (CANSA), the Family and Marriage Association of South Africa, various affiliations of the Hospice and Palliative Care Association of South Africa, and several community- and faith-based organizations which provide either hands-on care to those requiring care, or training, support and/or transport for home care volunteers. The Southern African Catholic Bishops' Conference and its associate agencies, as an example, have an AIDS Office which support over 100 community-based HIV/AIDS projects throughout South Africa, Namibia, Botswana and Lesotho. Most of these projects focus on home care, orphan support and AIDS education. Through an umbrella grant to the AIDS Office, the Catholic Relief Services directly support over 50 of these projects, which reach into communities where the need is greatest, particularly in rural areas (Catholic Relief Services, 2003)

Generous donations, from humanitarian organisations such as Princess Diana's The Work Continues Memorial Fund, have contributed to the development of home care services, including the expansion of the existing home-based care programme of the Helderberg Hospice in Somerset West into the Nomzamo and Lwandle rural communities, and an extension of the South Coast Hospice's services in KwaZulu-Natal towards a poverty-focussed, rural, home-based palliative care service (The Work Continues, 2003).

The National Department of Health's National Guideline on Home-based Care/Community-based Care, issued in 2001, uses the same definition for home care as the WHO-definition mentioned in section 2.3, i.e. "the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person's maximum level of comfort, function and health including care towards a dignified death". The AIDS epidemic, in combination with the increase in non-communicable diseases, the ageing population and specific challenges related to the formal health care system of the country, are factors included in the rationale for having a national guideline on home care (Department of Health, 2001: 1,2). The guideline's objectives include ensuring access to care and follow-up through a functional referral system; the integration of a comprehensive care plan into the informal, non-formal and formal health system; empowerment of the family/community to take care of their own health; shifting the emphasis of care to the community; empowering the client, the carer(s) and the community through appropriate targeted education and training at home (Department of Health, 2001: 8).

The target population for a home care programme, according to the Guideline, is people who need basic support services to continue to live and/or die in their community, without which they would have been prematurely, inappropriately or unavoidably moved to institutional care. It is intended that the programme be directed to both care recipients and caregivers, including frail older persons, people with moderate to severe functional disabilities, persons recovering from an illness or treatment, terminally-ill persons, people with HIV/AIDS or other debilitating conditions, and disadvantaged persons in need of such care (Department of Health, 2001: 3-4).

Diversity in range and orientation of services is encouraged in the document's principles of home care. Holistic care, including physical, social, emotional, economic and spiritual needs should be addressed in preventative, promotive, therapeutic, rehabilitative and palliative care, while being sensitive to culture, religion and value systems. Comprehensiveness is promoted in terms of interdepartmental, intra-departmental and multi-sectoral services (Department of Health, 2001: 3-4).

2.3.4 Differing country-specific examples, but comparable objectives

In societies with established home care services, a distinction is often made between formal and informal care, or care delivered by formal service providers and that offered by informal carers. This formal/informal distinction often represents the paid/unpaid care divide in home care programmes.

A range of formal home care services is available, predominantly in the industrialized world, and may be financed and organized by governmental organizations, NGOs or for-profit organizations. These services are often provided by professionals such as social workers, doctors and nurses, and/or para-professionals such as personal care workers, and can be offered on a long-, medium- or short term basis depending on the needs of the care recipient. In societies with traditional beliefs, traditional healers are increasingly recognized as an additional care resource. Formal care services may range from organized delivery of housekeeping assistance and cooked-meal delivery; to in-house training courses for both clients and carers; to home-health-care teams bringing high-tech medical and hospital technology to the client’s home (Surpin, 1988; Takahashi *et al*, 1996, cited in WHO, 1999b; WHO, 2002d: 9).

Vast differences exist among regions and countries in the methods of, reasons for, and infrastructure for home care, as can be seen from the three country examples above. This situation is most likely combined with differences in the infrastructure and opportunities available in hospitals, resident-institutions and other institutions of care. While substitution for acute hospital care in the developed world may refer to the periodic transfer of sophisticated hospital technology by a professional home-health-care team to the client's home due to a client's preference (cf. Surpin, 1988), it may refer in resource-poor societies to the temporary application of home remedies by family members due to the unavailability of transport to a hospital, or the absence of the required technology in the local hospital. However, from the country examples above, it is clear that even though contrasting specifics of home care exist across societies, home care in general has one or more of the following objectives: to prevent or delay institutionalisation of people in need of care; to substitute for long-term care institutionalisation; or to substitute for acute care hospitalization (WHO, 1999b: xiii; WHO, 2002a: 6).

2.4 INFORMAL CARE

2.4.1 Defining informal care/carers

Two broad definitions used by the WHO (2002d: 19) and Wiener (2003: 3), respectively, are "care given by relatives and friends to disabled individuals", and "unpaid care by relatives and friends", while Hooyman and Kiyak (2002: 308) defined 'informal care' as "unpaid assistance provided by family, friends, and neighbors in the areas of ADLs and IADLs". Pijl (2003: 27) quotes two definitions of informal carers which, respectively, were used in studies conducted in the United Kingdom and the Netherlands, i.e. "people who look after a relative or friend who need support because of age, physical or learning disability, or illness, including mental illness", and "persons who provide care, not in the context of a care profession, to someone in need of care in their direct circle of family and friends". The definition used by Great Britain's General Household Survey is "people who (are) looking after, or providing some regular service for, a sick, disabled or elderly persons living in their own or another household" (Maher & Green, 2002: x).

Pijl (2003: 27) is of the opinion that the word 'carer' on its own may lead to confusion, and that the specifications 'informal' and 'family' are often used to designate a difference from formal or professional carers such as nurses, social workers or physiotherapists. However, Pijl also means that both 'informal carer' and 'family carer' are inadequate, in that carers themselves may regard the term 'informal' as not doing justice to the importance and the actual burden of their work, while 'family' is not doing justice to the reality that neighbours, friends and other volunteers act as carers too.

A wide variety of definitions are available in the literature, and it seems that no internationally-accepted, uniform definition of 'informal care/r' is available. There may be an equally-wide variety of reasons for the lack of a uniform or standard definition, and it seems that Gubrium (1995: 267) summarized such reasons well when he suggested that it may be a symptom of "the often fuzzy contents and borders of caregiving encounters and the identities of the (caregiving and care-receiving) participants".

2.4.2 Providers of informal care

Informal care is largely provided by nuclear and extended family members, friends, neighbours, or other community members, who are not compensated in monetary terms for their carer responsibilities and tasks. Although the literature generally implies that informal carers are related in some way or the other to the care recipient (for example through being a friend, neighbour, relative or community member), non-relative and non-community volunteers too may be involved in informal care, either (a) on a basis informed by personal convictions, or through groups/teams from non-governmental, community-based or faith-based organizations. The WHO (2002d: 9) referred to (a) and (b), respectively, as 'independent volunteers' and 'organized volunteers'.

2.4.3 Nature and contents of informal care

Informal care is by far the dominant form of care throughout the world, and in terms of long-term care, informal care provision "dwarfs" the provision of care in nursing homes and that by paid home care workers (Wiener, 2003: 3). Informal care encompasses a wide range of activities, experiences and situations. It may include looking after an adult child with advanced multiple sclerosis, a frail parent, a quadriplegic young child, or a blind member of the community. Besides attending to a care recipient's physical needs, informal care may also include attending to someone's psycho-social, spiritual, housekeeping, shopping or transport needs. It may involve care over years in a life-long commitment to an individual with a permanent disability or incurable chronic disease, or it may be intermittent and sporadic when caring for someone with acute episodes of a chronic disease.

From the literature it is clear that informal carers are responsible for a wide variety of tasks and responsibilities in their carer roles, including:

- assisting in **personal care** with tasks such as bathing, showering, dressing, feeding, grooming, transferring, toileting and other aspects of personal hygiene;
- assisting with **medical and nursing care**, e.g. administering medication, changing colostomy bags, cleaning and dressing wounds, and treating bed sores;
- assisting with **housekeeping or domestic tasks**, e.g. house cleaning and tidying, doing laundry, and preparing meals;
- giving **social support**, e.g. at-home accompaniment, or escorting;
- giving **emotional support**, e.g. comforting, consoling, encouraging and pacifying;
- assisting with **life management**, e.g. managing the care recipients' financial affairs, doing shopping, fetching prescriptions, and paying bills; and
- assisting with or providing **transport**.

2.4.4 Research on informal care/rs in South Africa

Despite increasing growth rates in the older population, and despite a distinctive quadruple burden of disease that faces many shortcomings in the formal public health system and unaffordability of private health care in the majority of the nation, a dearth of research has been conducted on informal care/rs in South Africa. Studies focusing on the concept 'informal care' as referred to in the thesis were extremely scarce. Some studies are not directly comparable to the thesis study as they considered a wider concept of care, i.e. 'unpaid care', which includes, for example, routine parenting behaviour.

In research on ageing led by Ferreira, Gillis & Moller in the late 1980s, Chinkanda (1989) focused on urban African black people's attitudes towards the care of older persons, reporting that informal care by family members were "hardly available" in urban settings, and that72% of the respondents regarded homes for older persons as a more suitable form of accommodation. A decade later, Mokone (1999) wrote about the family's role as a support system for older persons and the challenges of caring for older persons. The latter source was not based on empirical research, but the author suggested that community-based services such as home health care, caregiver support programmes, respite care, day care facilities and luncheon clubs may be helpful to both caregiver and care recipient.

In 2002, a cross-sectional non-representative study on how households cope with the impact of the HIV/AIDS epidemic was commissioned by the Henry Kaiser Family Foundation and published in 2002. A range of issues was researched in 771 AIDS-affected households in four provinces, with a section focusing on caregiving by household members, showing that 68% of the carers were women or girls, and 23% were older than 60 years. In more than 40% of the households, carers had taken time off from employment or schooling to fulfil carer tasks at home (Steinberg *et al*, 2002).

A multi-method study was done by Uys (2002) in seven sites where the South African Hospice Association has implemented home care services. While the target study population was paid community carers in a home-based HIV/AIDS project, she also briefly referred to the unpaid informal care provided by family members. Uys (2002: 106) reported that the care given by these informal carers was “impressive”, albeit under difficult circumstances and at a real cost to themselves.

Akintola (2004) conducted an ethnographic study in a semi-rural setting among both informal carers (family members) and volunteer community carers of persons living with HIV/AIDS. Twenty out of the 21 interviewed carers were women, carrying out a variety of carer tasks, including physical care such as lifting and turning patients and assistance in walking, bathing, feeding and dressing; assistance with household chores and transport; moral and spiritual support; and general care of the children of the patient. Akintola's research concluded that caregiving is "very demanding", and that the cumulative demands lead to considerable stress. Four major kinds of stresses were identified, i.e. physical stress; psychological and emotional stress; economic stress and social stress. More valuable findings from Akintola's work include the adverse consequences of stigma that continues to be rife, affecting both caregivers and care recipients, and the extensive hardships and burden of carers who are mothers and spouses or partners, and HIV-infected themselves.

In 2001, Statistics South Africa published the country's first national time-use study which aimed at providing new information about paid and unpaid and labour in a national sample of 14 553 respondents 10 years or older. The study captured people's activities in a 24-hour diary with 30 minute slots. These activities involved 10 separate activity categories of which one was a broad category called "care of persons". This category was much broader than 'informal' care as utilized in the thesis study, and included physical care (washing, dressing or feeding) of children; teaching, training and instructing children; accompanying children to school or sports; physical care of the sick, disabled, or older household members; and supervising children and adults needing care. From this study it was clear that, similar to the patterns found in developed and other developing nations, women spend much more of their time on unpaid, reproductive type work than men, while men were more likely to be involved in paid work (Statistics South Africa, 2001: 82). For example, of those respondents reporting that they were in involved with the category called “care of persons”, 85% were women, while of those reporting that they were involved with the category called “work in establishments”, 60% were men (Statistics South Africa, 2001: 96).

Only one study was found with an exclusive focus on informal care by unpaid informal carers as defined in the thesis study. Commissioned by Age-in-Action and conducted by the Medical Research Council in 1999, about 600 informal carers were interviewed in a cross-sectional study in eight provinces in metropolitan, urban and rural settings. The study was not restricted to carers of older persons only, but included carers of persons with mental conditions, physical disabilities, sensory disabilities, cerebral palsy and advanced chronic illness such as cancer, stroke, Alzheimer’s and Parkinson’s disease—irrespective of their age. Both quantitative and qualitative data were collected about their experiences, needs, concerns and tasks as carers. As no list of informal carers were available, it was not possible to draw a representative sample, but valuable information about the characteristics, perceptions, knowledge, and caregiving responsibilities of the participating carers became available. Details about the content and duration of carer roles, the care recipient, the place of care, as well as the sources of information and support were also collected. The study found, inter alia, that 86% of the participants were female; over one-fifth were 60 years or older; over 60% spent on average more than 10 hours per day on caregiving activities; 28% were caring for over 10 years at the time of the study; and about one-quarter were not able to take any break or time off from his/her carer responsibilities. Large proportions of carers performed a combination of household tasks, health care tasks, and bodily care and hygiene tasks, while over one-fifth felt that they did not have the necessary knowledge and skills to perform these tasks. About one-quarter of the care recipients were bedridden, and nearly three-quarters could never make use of transport on their own. About one-quarter of the carers reported that their health and social life have been affected detrimentally as a result of their carer tasks (Joubert *et al*., 2002).

2.5 SYNTHESIS

For over 40 years, caregiving research has been conducted in many countries of the developed regions of the world. A wealth of literature on ‘long-term care’, ‘home care’ and ‘informal care’—both as separate concepts, and combined into the concept of ‘long-term informal care at home’—is available from the developed world, and it is clear that long-term care has become a key health, social security, financial and research issue in many of these societies. Research on caregiving cuts across disciplines, including the social sciences, public health, nursing, psychiatry and the humanities (Gubrium, 1995). The literature on ‘informal care’, in particular, often reflects developments from basic exploratory and descriptive studies to specialized studies that focus in detail on a particular aspect of informal care such as burnout and coping mechanisms in individual carers; gender and ‘race’; programmes of support; policy and economic implications; and the application of conceptual frameworks and theories.

In contrast, the subject of caregiving in developing nations has not received similar attention in the published literature—despite international concern that long-term care needs are drastically increasing in the developing world. For example, very few publications were found that relate to informal, home or long-term care—either as separate concepts, or combined—in Africa, while it is presumed that long-term informal care in the home setting would be more prevalent in this region compared to, for example, Western Europe, North America or the Balkan countries.

From the selected definitions and country examples in this chapter, it is clear that differences exist among countries in the policies, goals, resources and activities associated with long-term care, home care and informal care. Part of the explanation for such differences can be attributed to country-specific stages of demographic and epidemiological transition, different levels of economic development, and different levels of access to institutional or other formal care services.

Against the background of South Africa's demographic transition into one of the oldest populations in Africa, but the low public priority given to older persons in health and social transformation initiatives; and given the country's epidemiological transition into a unique quadruple burden of disease with extensive long-term care needs (compare section 3.2.2.2), but the shortcomings associated with formal health care delivery and affordability, it is a matter of serious concern that there is currently no formal long-term care programme or insurance scheme with an exclusive emphasis on long-term care.

Formal home care guidelines and programmes have recently been introduced in South Africa, and although appreciated, they have limited commitment to and concern about informal caregivers who need to stand in for the shortages and deficiencies in formal long-term care. Uys (2002: 108) also warns against the issue of coverage (there is a service available in the area or country) versus penetration (every potential client is served), which she means is a perpetual problem in developing countries.

Chapter 3

CONCEPTUAL FRAMEWORK AND THEORETICAL AND EMPIRICAL BASE OF THE STUDY

3.1 INTRODUCTION

While Chapter 2 reviews the caregiving literature with an emphasis on enhancing the understanding of informal care in the home setting to persons with long-term care needs, this chapter attempts to integrate the thesis study into a conceptual framework and theoretical context.

The impacts of the demographic and epidemiological transitions in South Africa form the basis of the rationale for the study. Aspects of these transitions, and its culmination in the health transition, are presented in this chapter to conceptually frame the study. Particular attention will be given to population ageing (as an outcome of the demographic transition) and the burden of disease (as an outcome of the epidemiological transition) experienced in the country.

To integrate the study into a broader theoretical context, literature on a feminist approach to informal care has been consulted. Additionally, while the large majority of the international literature on informal care refers to older persons as care *recipients*, a few studies in South Africa, as well as age patterns emerging during analyses of the thesis data, prompted the student to examine empirical research studies reporting about older persons as care*givers*.

3.2 CONCEPTUAL FRAMEWORK OF THE STUDY

3.2.1 The Demographic Transition Theory

Over the past half a century, the interpretation of past population change and the expectations about future trends, rest to a large degree on a body of observations and explanations referred to as the Demographic Transition Theory.[1] In this theory it is argued that subsistence, low-income societies are characterized by high birth and death rates, with the birth rates relatively stable, and the death rates fluctuating, resulting in low population growth rates. Reasons for high fertility included high mortality, the economic value of children, and the lack of opportunity for individual advancement. Then, as the economy changes to a more modern, interdependent and specialized economy, death rates decline, and continue to decline under the impact of better societal organization and improving medical knowledge and treatment. Somewhat later, the birth rate also starts declining, but due to the lag in time before birth rates decline, population growth is rapid at this stage. As further reduction of the mortality rate becomes harder to attain, the birth rate approaches the same levels as the death rate, and a more gradual rate of population growth is re-established as at the onset of the transition. In the absence of pandemics, wars and natural disasters, the mortality rate remains then relatively stable over the years, and the birth rate may fluctuate from year to year as a result of being responsive to voluntary decisions rather than to deeply-imbedded customs (Coale & Hoover, 1958: 12-13).

The term “demographic transition”, in simplistic terms, refers thus to a gradual

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[1] The arguments whether the Demographic Transition Theory qualifies as a theory, paradigm or conceptual framework are acknowledged, and the work that has been done around different forms of the demographic transition (cf. Coale & Watkins, 1986) is recognized. However, for the purpose of the thesis, population ageing are perceived as an outcome of the population’s mortality and fertility changes as assumed in the classical Demographic Transition Theory.

process whereby a society moves from high to low rates of mortality and fertility. The transition is characterized first by declines in infant and child mortality, while fertility remains high. This initial decline in mortality among younger ages generates a younger population structure. Hereafter, fertility begins to decline and adult mortality rates improve, which is usually the period when populations begin to age (Lee, 1994; Kinsella & Velkoff, 2001). It can be argued that control over unwanted births and early mortality leads to reduced age-specific fertility and mortality rates, and gradually to a fall in births, as well as to a greater probability that those born will live longer. Golini (1999: 46) sees this as the mechanism that links the process of demographic transition to population ageing.

3.2.1.1 Population ageing as an outcome of demographic transition

Population ageing, or demographic ageing, is hence perceived as an outcome of a population's demographic transition, referring to an increase in the relative number of older people (60 years or older)[2] in a population, coinciding with a decrease in the relative number of younger people (0-14 years) in the same population, resulting in a changing age structure and a higher median age of the particular population. In simplistic terms, it has to do with the process in which persons aged 60 years and older constitute an increasingly larger proportion of the total population.

Three principal factors contributed over the last century to the process of population ageing in almost all the countries of the world, i.e. (i) fluctuating fertility rates, (ii) reduced mortality rates, and iii) increased migration endeavours.

a) The role of fertility

Fertility decline has been the most prominent historical factor in the ageing of populations, and plays a twofold role in the process of population ageing which can be called (i) an immediate, relative effect and (ii) a postponed, absolute effect. In the former, prolonged or persistent lowered fertility brings about declines in the proportions of children, and, accordingly, effectuates increases in the proportions of older persons. This effect is referred to as ageing from the base of the population structure (Pressat, 1972).

Population momentum, through a complex interaction between the total fertility rate, the number of fertile women, and the number of births on the one hand, and population ageing and population growth on the other, makes this effect not all that straightforward. Population ageing will not occur until the drop in fertility generates either a parallel decline, or constancy, in the number of births. Births in absolute numbers determines whether the base of the age structure remains wide and the population hence stays young, or shrinks and the population becomes older. Decreased fertility does not necessarily mean decreased births, particularly in cases where long-term past high fertility brought about large cohorts of fertile women which ‘outpaces’ the declines in fertility. This means, that, even in the presence of fertility decline, the number of births will increase and the population will indeed be rejuvenated. The opposite may also happen. In cases where a population has experienced long-term low levels of fertility and hence a decline in births, it may continue to age, despite a rise in fertility. The population will continue ageing until the rise in fertility is persistent and sizeable enough to counterbalance

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[2] As currently promoted and utilized by the United Nations and the World Health Organization, the term ‘older persons’ or ‘older population’ in the thesis refers to persons 60 years or older. However, some publications use 65 years as a cut-off point, and a few references will be made

the drop in the number of fertile women and produce an increase in births (Golini, 1999; Keyfitz, 1971; Preston, 1986).

In the postponed, absolute effect, on the other hand, temporal or incidental lowered fertility as experienced, for example, during World War I and II, can lead over time to a drop in the growth rate of the older population as the smaller birth cohorts reach older ages. An example is the decline in the growth rate of the older population in most developed countries which began in the mid-1990s and will continue into the early 2000s, corresponding to lowered fertility during the Great Depression and World War II. The postponed, absolute effect is also possible through temporal *increased* fertility as experienced *after* World War II. Around 2008 till about 2018, these post-war Baby Boom cohorts are projected to result in augmenting the numbers of older persons significantly (Kinsella & Taeuber, 1993: 9; Kinsella & Velkoff, 2001: 7, 12).

b) The role of mortality

It would be an oversimplification to argue that reduced death rates lead to increased life expectancy, which in turn leads to increased numbers of older persons in a population. Mortality's contribution to ageing is a more complex one, since reduced mortality through the history also resulted in increased numbers among the younger cohorts of a population. Mortality rates in a population are usually characterized first by declines in infant and childhood mortality as infectious and parasitic diseases are reduced. This implies improved life expectancy at birth, while fertility tends to remain high. Large birth cohorts, expanding proportions of children relative to adults, and a younger population age

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to this population too with an indication that the 65+ population is being referred to.

structure are hence produced (Coale, 1974; Kinsella & Velkoff, 2001: 17; Lee, 1994).

Generally, it is when fertility declines and continue declining until successive birth cohorts eventually become smaller, that adult mortality rates improve, and populations begin to age.

Hofmeyr and Mostert (1992: 21-22) argued that the main historical reasons for increased life expectancy, which includes improvements in the standard of living, the development of modern medicine, and the institution of public health measures, resulted specifically in a reduction of exogenous mortality, which effectuates mortality declines at *all ages*. Mortality reduction becomes a factor in population ageing specifically when endogenous mortality, essentially deaths occurring during and associated with the process of ageing, is being addressed. This brings about decreasing death rates among people of *older ages*, thus leading to ageing at the top of the population structure.

In general thus, in the process of population ageing, mortality reduction usually at first thus leads to the rejuvenation of a population as infant and child mortality rates are reduced by the treatment or eradication of infectious and parasitic disease. As a population moves in time through different stages of its demographic transition, declines in mortality only at a later stage contribute to population ageing.

c) The role of migration

International migration may play a role in the ageing of populations, but it is generally known that international migration usually does not play a major role in population ageing (Kinsella & Velkoff, 2001: 17; Hofmeyr & Mostert, 1992: 22). However, population ageing can be influenced in small nations, for example in certain Caribbean populations where emigration of working-age adults, immigration of older retirees from other countries, and return-migration of former worker-emigrants who are above the average population age, all contribute to the ageing of these populations (Kinsella & Velkoff, 2001: 17).

Internal migration may affect ageing in regional or local populations, for example where a specific region or area has limited employment opportunities, but offers attractive retirement settings, and working-age people emigrate in large numbers, while retirees immigrate in large numbers.

3.2.1.1.1 Population ageing globally

Most, if not all nations, at a time in their history, had a youthful age structure with a large proportion of the total population under the age of 15. However, virtually all nations are now experiencing growth in their numbers of older persons (Kinsella and Velkoff, 2001: 7, 17). In 1950, the proportion of older persons (60 years or older) in the world population was 8%; in 2000, it increased to 10%; and in 2050, it is projected to reach 21%. These proportions translate to an estimated 205 million older persons in 1950; 606 million in 2000; and 2000 million in 2050—reflecting a tripling of this age group over two consecutive 50-year periods (UN, 2002a). These increases in older persons will happen simultaneously with a decrease in children as the proportion of children is projected to drop by a third from 30% in 2000 to 21% in 2050 (UN, 2002b).

With a simple calculation, the dimension of population ageing is sketched rather vividly by Kinsella and Velkoff (2001: 7): at midyear 2000, the global population aged 65 years or older was estimated at 420 million persons, showing an increase of 9.5 million since midyear 1999. The net balance of the world's 65+ population grew by approximately 795000 persons each month during this year, a calculation which translates to 26500 persons per day, and 1105 persons per hour reaching the age of 65.

In developed nations, generally, the population 65+ accounts for high proportions of the total population, ranging from 12 to 16% in most developed countries at the turn of the millennium. Among the world's major regions, Europe has had for many decades the highest proportion of population 65+. Except for Japan, the world's 25 oldest countries are all in Europe, and the five demographically-oldest countries during 2000 were Italy with 18,1% of its population 65+, Greece and Sweden each with 17,3%, Japan with 17%, and Spain with 16,9%. North America and Oceania also have high percentages, with the United States and Canada, respectively, at 12,6% and 12,7%, and Australia and New Zealand, respectively, at 12,4% and 11,5% in 2000 (Kinsella & Velkoff, 2001).

While population ageing has become a well-publicized phenomenon and public concern in most developed nations, it is not a similarly-publicized issue and public concern in developing nations—despite the fact that many developing countries are ageing at a much faster rate than countries in the developed world, that the most rapid increases in older populations are currently in the developing world, and that the numbers of older persons in developing countries currently exceed those in developed nations. The current aggregate growth rate of the older population in developing countries is more than double that in developed countries, and 77% of the world's net gain of persons 65+ from midyear 1999 to midyear 2000, occurred in developing countries. This implies that approximately 612 000 people per month had turned 65 in developing nations (United Nations, 2002a; Kinsella & Velkoff, 2001).

The average annual growth rate of the population 65+ in developing countries began to rise in the early 1960s, has generally continued to increase until recently, then had a brief downturn related to lower wartime fertility, but is expected to rise beyond 3,5% annually from 2015 through 2030 (Kinsella & Velkoff, 2001: 7).

Fertility change has been more recent in the developing world, as most regions have achieved reductions in fertility rates only over the last 30 years. This partly explains the lower proportions of older persons in developing nations. However, proportions by themselves may not give a real sense of the ageing momentum. For example, although the projected change in the percent persons 65+ in Sub-Saharan Africa from 2000 to 2015 is very small, i.e. from 2,9% to 3,2%, the size of the 65+ population is expected to increase from 19,3 million to 28,9 million people. Drastic increases in 65+ populations are projected from 2000 to 2030 in many other developing countries, such as a 258% increase in Columbia, 227% in Mexico, 210% in Egypt, 193% in Marocco, 153% in Pakistan and 41% in Malawi (Kinsella & Velkoff, 2001: 9-12).

It is clear that the timing and rapidity of population ageing are being experienced differently in developed and developing nations. Whereas population ageing has evolved gradually as a result of improved living standards over a long time since the industrial revolution in developed nations, it is occurring in a much shorter period of time in most developing nations due to rapid fertility declines and medical interventions effectuating declines in mortality. The rapidity and compressed time frame within which these changes are occurring in the developing world, and the fact that it is occurring on relatively larger population bases than in the developed world, pose particular challenges to nations with lacking resources and infrastructure.

3.2.1.1.2 Population ageing in South Africa

Despite shortened average life expectancy resulting from the impact of HIV/AIDS, South Africa's population is ageing, and—mainly through declining fertility rates and pre-AIDS increases in life expectancy—South Africa's population will continue ageing over the next 10 to 15 years (Haldenwang, 2001; Joubert *et al*., 2003) The country accommodated 3.28 million older persons (60 years or older) during the 2001 population census, accounting for 7.3% of the total population (Statistics South Africa, 2003). These figures make the South African population demographically one of the oldest populations on the continent. It is projected that by 2015 the proportion and number of older people will increase to 8.8% and 4.25 million respectively.[3] In 2001, South Africa had an ageing index of 23 older persons for every 100 children 0-14 years old, which is projected to rise to 30:100 in 2015. These recent projections confirm the earlier work of Haldenwang (2001) as well as previous ASSA projections (ASSA2000 as used in Joubert *et al*., 2003) by continuing showing that South Africa's population will continue ageing in at least the short to medium-term future.

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[3] See footnote 1 in Chapter 2.

The aggregate figures, however, conceal the diversity in ageing patterns among the country's historically-defined four population groups[4]. For example, the pyramid shape of the age structure of the African Black population corresponds with that of most developing countries in the early stages of demographic transition with relatively high fertility and mortality rates, a broad base with large numbers of children, and a narrow apex with a small proportion of older people—characteristic of demographically young populations. White's age structure compares with some of the world's developed countries, resulting from lower fertility rates that evolved over several decades, with a narrower base and wider apex compared to that of the African Black age structure. The population age structure of Asians is in an intermediate position between those of the Whites and Coloureds, and that of the Coloureds, in an intermediate position between those of the Asians and Blacks. During Census 2001, Whites had about double the proportion of older persons (15.9%) compared to Asians (7.8%), African Blacks (6.4%) and Coloureds (6.4%) (Statistics South Africa, 2003). The differences in these proportions are reflected in the differences in the age structures, which are mainly attributable to different stages of each population group's demographic transition.

For planning purposes it is important to differentiate between the proportions of older persons within a particular population group, and the population group proportions within the total number of older persons in South Africa. Whereas the in-group proportions of the population 60+ show that population ageing is more pronounced in Whites, African Black older persons made up the largest proportion

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[4] The population group classification is in accordance with the Population Registration Act of 1950. This classification has been used to highlight issues that may portray effects of historical disparities, and the student do not subscribe to this classification for another purpose.

of all older persons in the country, i.e. 69%, while White, Coloured and Asian older persons, respectively, made up 21%, 8% and 3% of the total population 60+ (rounded figures; Statistics South Africa, 2003)

3.2.2 The Epidemiological Transition Theory

The changing age structure of a population resulting from its demographic transition is generally associated with a transformation of cause of death patterns in the population. As fertility declines and populations begin to age, the prominent causes of death change from those associated with childhood mortality to those associated with older age (Kalache, 1996). This latter transition has been termed the 'epidemiological transition', referring to the long-term and complex changes in the cause of death patterns and changes in health and disease that occur during demographic and socio-economic transformation in a population (Mosley *et al.*, 1993: 676; Steyn & Schneider, 2001: 5).

A theory of epidemiological transition was initiated by Omran (1971) who posited different stages or sequences of epidemiological transition in a population, identifying three phases, i.e. the age of pestilence and famine, the age of receding epidemics, and the age of degenerative and man-made diseases. Because of progressive declines in mortality rates from some chronic diseases associated with the steady gains in life expectancy among older persons in the United States and other industrial countries, Olshansky and Ault (1986, cited in Mosley *et al.*, 1993: 676) proposed a fourth phase in the epidemiological transition, i.e. the age of delayed degenerative diseases.

Simplistically-stated, Omran's theory refer to a long-term change in the leading causes of death, from infectious and acute causes, to chronic and degenerative cause. However, based on observations in some large middle-income populations, Frenk *et al*. (1989) proposed changes to Omran's work with their protracted-polarised model of epidemiological transition, suggesting the long-term co-existence of infectious and lifestyle diseases in the same population.

3.2.2.1 Epidemiological transition in South Africa

To describe aspects of a country's epidemiological transition, it is necessary to assess patterns of change in causes of death, as well as overall changes in health and disease that occur in the process of the country's demographic and socio-economic transformation. Analyses of South African mortality and morbidity patterns during the mid-1980s indicated a dual profile of communicable and poverty-related conditions on the one hand, and emerging non-communicable conditions on the other (Bradshaw *et al.*, 1992). During the late 1990s, research findings pointed to a triple burden of disease due to the added burden from high rates of injuries (Butchart & Peden, 1997).

Recent research and careful interpretation of the mortality profile in South Africa, however, have indicated that the South African epidemiological profile has built up into a unique quadruple burden of disease (Bradshaw, *et al.*, 2003), with the major addition of HIV/AIDS to a combination of continued pre-transitional conditions related to under-development and poverty (e.g. diarrhoeal diseases and tuberculosis), non-communicable conditions traditionally associated with a Western lifestyle (e.g. cardiovascular disease and neoplasms), and high rates of injuries (e.g. homicide and road traffic accidents).

3.2.2.2 Burden of disease in South Africa

The current stage of South Africa's epidemiological transition implies a diverse and heavy burden of disease in the population. 'Burden of disease' is an internationally-recognized term that refers to a systematic and comprehensive scientific approach to measuring the health problems of a population by studying ill-health and causes of death in that population.

Estimates from the South African National Burden of Disease Study (SA NBD) have indicated that, for 2000, the largest single cause of death was HIV/AIDS which accounted for 30% of deaths among all ages. Ischaemic heart disease, homicide/violence, stroke, and tuberculosis are next in the ranking, each accounting for about 6% of all deaths. The next five largest single causes were lower respiratory infections, road traffic accidents, diarrhoeal diseases, hypertensive heart disease, and diabetes mellitus (Bradshaw *et al.*, 2003: 31-32).

With particular reference to the provision of care, it is important to consider non-fatal health outcomes in addition to the causes of death. Non-fatal outcomes such as morbidity, injury and disability, contribute substantially to burden of disease measures, and can change the ranking of diseases that are based on the impact of mortality alone. If every disease caused morbidity in known proportion to the mortality it causes, then mortality rates would have been an adequate proxy for the overall burden of ill-health and for the contribution to the burden of each specific disease or cause. However, some disability and disease conditions, such as nervous system disorders (e.g. multiple sclerosis, epilepsy and Alzheimer's disease), mental disorders (e.g. schizophrenia), and affective disorders (e.g. bipolar depression) can cause substantial morbidity in proportion to its mortality.

Moreover, some conditions such as impairments of the sense organs, skin disease and some oral conditions result in morbidity, but essentially are non-fatal. As such, mortality measures capture only a portion of the burden of disease (Murray *et al.,* 1992: 113).

To adjust for non-fatal health outcomes, the disability adjusted life year (DALY) was introduced by the Global Burden of Disease Study.[5] DALYs were calculated in the South African National Burden of Disease Study, showing that the burden of some diseases categories is severely underestimated when non-fatal outcomes are disregarded. It is clear that the major part of the burden for some disease categories indeed is from disability, and not from mortality, in particular for nervous system disorders, mental disorders, sense organ conditions, respiratory disease (e.g. chronic obstructive pulmonary disease), and musculo-skeletal diseases (e.g. osteoarthritis and rheumatoid arthritis) (Bradshaw *et al*., 2003).

3.2.3 The health transition and its implications

The aggregate processes at work in the demographic and epidemiological transitions have become known as the ‘health transition’, referring to the combined changes in fertility, mortality, risk factors, cause of death and morbidity profiles, as well as health systems’ response to these (Mosley *et al.*, 1993: 674; Frenk *et al.*,

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[5] A detailed explanation of the DALY measure, the principles on which it is based, its social values, computation, and critiques are beyond the scope of the thesis, but an over-simplified explanation could entail the following: The DALY is a summary measure of population health which combines information on fatal and non-fatal health outcomes. Two concepts, ‘health expectancies’ and ‘health gaps’ have been developed as complementary classes of summary measures of population health. The DALY is an example of a health gap, assessing the difference between the actual population health and some specified norm by measuring the future healthy years of life lost due to each incident case of disease or injury. The DALY for a condition comprises the sum of the Years of Life Lost (YLLs) and the Years Lived with Disability (YLDs) for that condition, weighted according to the severity of the disability (Bradshaw, *et al*., 2003: 3).

1989).

As longevity increases, the prevalence of frailty, chronic disease and disability raises through a tendency of declining physical, physiological, mental and cognitive functional capacities in ageing individuals (WHO, 2003). In this way, the ageing populations contribute to an increasing number of people who need care.

In the developed world, substantial increases in life expectancy at older ages have lead to an increasing demand for care programmes and services for older persons. A United Nations Expert Group on Care Giving and Older Persons reported that while the majority of older persons continue to lead healthy and resourceful lives, the risk of frailty, disability and disease grows with increasing age, particularly so among the fast-growing oldest-old segment of the population (UN, 1997). Chronic conditions are responsible for a large burden in terms of both mortality and morbidity in developed regions (Mathers *et al.*, 2002). Such conditions largely are lengthy and require continuity of care which often needs to be provided over long periods of time (WHO, 2001).

Virtually all developing nations are ageing too where the increase in the numbers and proportions of older persons is generally occurring at a faster rate than in developed countries, and increasing care demands are experienced at levels of income that are far lower than that which existed in the developed world when these needs emerged (Brodsky *et al.*, 2003). Additionally, most developing countries are still struggling to control pre-transitional causes of morbidity and mortality, while simultaneously bearing the burden of chronic and degenerative disease too. It seems inevitable that health systems will be facing unprecedented increases in the volume and diversity of health and health-related problems and challenges which need to be addressed, including challenges related to caregiving.

The impacts of demographic and epidemiological change are also evident in South Africa, where the simultaneous effects of population ageing and a large burden of disease, including that of the unprecedented HIV/AIDS epidemic, are currently being felt. Previous sections indicated that the country is faced with challenging problems related to a uniquely large and diverse burden of disease. One such challenge relates to caregiving in a setting with resource constraints and where the formal health care system is not adequately geared for dealing effectively with the diversity and extent of the burden of disease.

3.3 THEORETICAL AND EMPIRICAL BASE OF THE STUDY

One of the objectives of the study is to investigate gender differences in relation to the likelihood of being a carer. Through this objective, and seeking support for Hypothesis 1, part of the study found its base in feminism. Another objective seeks to investigate age differences in relation to the likelihood of being a carer. This part of the study, seeking support for Hypothesis 2, found its base in the findings of selected empirical research studies.

3.3.1 Theoretical base: Feminism and a feminist approach to informal care

The concept of gender, and how it creates socially-constructed differentiation between men and women, is central to feminist work. Feminism concerns women's similarity to, or their dissimilarity from men. It seeks to find what differences there are beyond the most basically biological differences and how these differences are caused (Evans, 1995: 3). According to Young (1990, as cited in Evans, 1995: 3) feminism means seeking for women the same opportunities and privileges that society gives to men, while Giddens (1994: 182, 742) defined feminism as “the struggle to defend and expand the rights of women”, and “advocacy of the rights of women to equality with men in all spheres of life”.

In their work, feminists reflect a commitment to critiquing mainstream theories for the neglect of the gendered nature of work life, family life, and social stratification (Calasanti & Zajicek, 1993). Feminists have prompted studies of women’s activities and attitudes in various areas of social life where they previously were largely ignored. One such area has shown how misleading it was to define ‘work’ as ‘paid work outside the home’, and feminist authors have been largely responsible for pointing out and analyzing the importance of housework (Giddens, 1994: 182).

Finley’s (1989: 79) opinions included that, similar to child care and housekeeping, informal caregiving is a type of family labour. Arber and Ginn (1990: 429) wrote that, during the early 1980s, the term (informal) ‘carer’ did not exist in Britain, to the extent that it did not merit an entry in dictionaries. Why the term entered the public domain of official statistics, relates to the aftermath of the 1970s when community care and the social consequences of demographic ageing became areas of increasing political concern and policy interest. Feminists started writing about the unpaid domestic labour of women, and carers were highlighted as a social group with a common problem and interest. They emphasized how women’s labour market participation was restricted by caring roles and how women were disadvantaged in social security systems (compare Charlesworth *et al.* (1984), Finch and Groves (1982; 1983), and the Equal Opportunities Commission (1982), all cited in Arber & Ginn, 1990).

Similarly in the United States, concerns about the public costs associated with demographic changes in the age structure of the population have increased the attention to the role of families in caring for dependent older persons. As the 1990s witnessed the decentralization of the federal government's role in caring for vulnerable members of society, feminists pointed out that women disproportionately would bear the negative repercussions of this shift in the social contract to 'self-reliance' and 'personal responsibility' (Hooyman & Gonyea, 1999: 149-150).

Socialist feminist theory refers to inequities in the gender-based division of work in which women are confined to activities such as childrearing, performing personal services for adult men, doing specified forms of productive labour with little prestige attached to it, and housework. A feminist approach to informal care argues that women have historically been oppressed within the home and the labour market. This is reflected in the invisibility and lack of compensation for their work at home, and their low wages in the labour force (Hooyman & Gonyea, 1999: 151; Marshall, 1996). Socialist feminists hence examine caregiving in the light of women's differential access to power in the paid labour force, childrearing, and unpaid housework throughout their lives (Arber & Ginn, 1990; Garner (1999) cited in Hooyman & Kiyak, 2002: 270).

Feminists concern the topic of informal care with an interest in the gender-specific amount and type of care provided, as well as the differential consequences of gender-based care responsibilities. Additionally, feminists highlight that caring for relatives across the life span has severe negative repercussions for women's health and economic status in old age, so that many women lack a choice in determining the conditions of their own ageing. Gender-based differences in informal care responsibilities have limited women's economic independence and personal rights, resulting in higher female rates of poverty across the life span, and especially in old age. A feminist approach seeks to make visible, and validate the importance of women's daily experiences as informal caregivers, and seeks to ensure that both men and women have choices in carer responsibilities, and in how they balance caregiving and employment (Hooyman & Gonyea, 1999: 152; Arber & Ginn, 1990).

Feminist thinking and concern about gender in caregiving are supported by research showing that the majority of informal carers are women (Dilworth-Anderson *et al*., 2002: 256; Editor, 2003: 1; Hooyman & Gonyea, 1999: 150; Ingersoll-Dayton *et al*., 1996; Stone *et al*., 1987). In terms of volume, intensity and frequency of care, Finley (1989) and Stoller (1983) found that the bulk of care is provided by women, while Yee and Schulz (2000), Neal *et al*. (1997) and Allen (1994) found that women spend more time on carer tasks than men.

Feminist researchers further emphasize that, consistent with a gender-based division of labour, men and women display different patterns of caregiver assistance, and that there are differences in the type of care given by women and men, as shown in the work of Horowitz (1985), Miller and Cafasso (1992), Chang and White-Means (1991) and Stoller (1990).

Another area of feminist work in informal caregiving research has shown gender differences in the consequences of caregiving. While Horowitz (1985) and Stoller (1983) found that women experience greater negative consequences of caregiving than men, Kramer and Kipnis (1995) and Anastas *et al*. (1990) showed that women who combine work and care, experience a more negative effect on work-family conflict and work-role strains. The study of Miller and Cafasso (1992) found higher levels of burden and depression in female carers than in their male counterparts.

Furthermore, Qureshi and Walker (1989, cited in Hooyman & Gonyea, 1999) and Ingersoll-Dayton *et al*. (1996) have shown the central role of gender in the hierarchy of obligation to older relatives. This hierarchy is reflected in their findings that, after spouses and daughters, it is daughters-in-law (not sons), and sisters (not brothers), who are likely to provide the care.

3.3.2 Evidence from empirical studies: Older persons as caregivers

The literature demonstrates that older persons are studied more readily as *recipients* than *providers* of care. Although there is limited research studies conducted on either in South Africa, there is evidence of increased chronic conditions associated with increased age, and probably thus increased needs for long-term care as people age. For example, data from the 1998 South African Demographic and Health Survey (SADHS) reflected significant increased prevalence of chronic respiratory conditions, hypertension and obesity with increased age (Norman *et al*., 2001), and disability data from the 2001 Census illustrate increased levels of disability with increased age (Joubert & Bradshaw, 2004). Demographic ageing globally has brought along a perceived social problem and political concern about the growing number of older persons as manifested in pension debates, fears of intergenerational conflict, and concerns about the costs of health and welfare services of older persons (Arber & Ginn, 1990: 431). This 'social problem' perspective has labelled older persons as a dependent and unproductive part of a society, and has contributed to the stereotyping of older persons as *recipients* of care. Indeed, a very large component of the international caregiving literature focuses on older persons as care recipients, while far less attention is being given to older persons as care*givers*.

A few studies, however, have recognised that older persons are not only recipients of care, but also providers of different kinds of care through, for example, caring for their spouses, looking after grandchildren, doing voluntary work in the community, and doing unpaid domestic work for their adult children (compare Arber & Ginn (1990: 451); Nissel & Bonnerjea, cited in Arber & Ginn (1990); Parker, cited in Arber & Ginn (1990); Ungerson, cited in Arber & Ginn (1990). In the US, studies such as those of Goodman and Silverstein (2002), Pebley and Rudkin (1999), and Thomas, Sperry and Yarbrough (2000) focused on grandparents' role in caring for their grandchildren, while Mutchler and Baker (2004) conducted a critical analysis of grandparent-caregivers data that had been collected during the Census 2000 Supplementary Survey. Indeed, the 1996 Welfare Reform Act requires the United States Census Bureau to determine how many grandparents are serving as carers to a grandchild, and whether that care is of short or long duration.[6]

A few South African studies also acknowledge the caregiving contributions of older persons to their families. It is a well-known phenomenon in South Africa that many older persons, particularly those in multi-generational households, assist in raising their grandchildren, which may include caring for sick and disabled ones (Joubert *et al*., 1998a & b; Møller & Sotshongaye, 1996; Brindley, as cited in Moller & Sotshongaye, 1996). Additionally, it is acknowledged that the AIDS epidemic has left many affected older persons with little choice but to care for their AIDS-sick offspring, orphaned—at times AIDS-sick—grandchildren, and/or other AIDS-affected relatives (Department of Social Development, 2003; Ferreira & Brodrick, 2001; Ferreira *et al*., 2001; Johnson *et al.*, 2003).

It is suspected that the AIDS epidemic served as a facilitator of increased research studies about older persons as providers of care as defined for the thesis study. For example, extensive work has been done in the United States by Poindexter and Joslin and their respective colleagues. HelpAge International and the International HIV/AIDS Alliance (2003) published a policy report with information about older persons as carers of orphans and vulnerable children, referring to situations in countries such as Cambodia, India, Kenia, Mozambique, Sudan, and Zambia. A leading contribution towards acknowledging the care provided by older persons is found in Knodel and colleagues' extensive research in Thailand,

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[6] Some studies about care provided by older persons do not necessarily refer to the concept of caregiving as defined for the thesis study, but include routine tasks of parenting, rearing, nurturing and socialization of children. It may therefore, strictly spoken, be not appropriate to refer to these studies in this section. They were nonetheless included, given the possibility that the difficulties, problems, burnout and related experiences by older persons with child-rearing responsibilities may be comparable to the difficulties, problems and burnout experienced by older informal carers who (as stated in the thesis definition) look after someone with frailty,

showing that older persons are commonly involved with the living and caregiving arrangements of persons with AIDS (compare Knodel *et al*., 2000; Knodel *et al*., 2001; Knodel & Saengtienchai, 2001; Knodel & VanLandingham, 2000). This Thai study showed that older persons provided care for 72% of adults who died of AIDS. Overall, parents were the most common carers (65%) of those dying of AIDS, ahead of spouses (35%) who were the second most common carers. The large majority of parents (85%) were 50 years or older at the time their child died, and almost half of these were 60 or older (Knodel *et al*., 2001; Knodel & Saengtienchai, 2001).

In Africa, similar levels of parental involvement as primary carers were found in a series of surveys in Uganda (Ntozi & Nakayiwa, 1999). A Zimbabwean study has found that 72% of persons who indicated that they were the main carers of persons with AIDS, were 60 years or older (World Health Organization, 2002f), while a non-representative study of 771 AIDS-affected households in four provinces of South Africa has shown that 23% of the carers were 60 years or older (Steinberg *et al*., 2002).

The majority of the small number of empirical studies reporting about older persons as informal carers to persons who need care beyond that usually expected from a healthy adult or child, have a worrying common message, namely that older persons’ physical and mental health, social life and financial well-being often are adversely affected. This concern, combined with the particularly large burden of disease in the South African child and young adult population (compare

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disability or ill-health who cannot cope on his/her own.

Bradshaw *et al*., 2003), have encouraged the student to investigate the likelihood of caregiving in older South Africans.

3.4 SYNTHESIS

The literature shows that the health transition in South Africa, through the demographic and epidemiological transitions, has brought along an ageing population and a quadruple burden of disease. These outcomes, through increased levels of frailty, disability and ill-health, contribute to an increasing number of persons who need health and related care. Given the resource constraints in formal public health and welfare care services, many people in need of care have little choice but to rely on informal caregiving in the home setting.

While informal care in the home setting in South Africa has been delivered for many years, if not centuries, to people who needed assistance with performing ADLs and IADLs, an increased need for such services has been created by different circumstances, including the following:

- a particularly heavy burden of disease, with exceptionally high levels of AIDS morbidity and intentional injury, as well as a growing burden of chronic disease (Bradshaw *et al*., 2003);
- continued ageing of the population (Haldenwang, 2001; Joubert & Bradshaw, 2004) with expected increasing proportions of the population suffering from debilitating chronic and degenerative diseases (WHO, 2003);
- the low levels of medical insurance and hence the unaffordability of private care in the majority of the nation’s people (Department of Health *et al*., 2002); and

- a shift towards de-institutionalization in the areas of frail care, mental health care and physical disability care (MWPD, 1997; Department of Welfare, 1997).

One of the subjects of concern in feminist theory is informal care with a specific interest in gender-specific manifestations and experiences in the provision and consequences of such care. While gender-based divisions in the volume, intensity, frequency, type, burden and consequences of care have been investigated in advanced analyses in the international literature, this thesis draws on feminist theory to investigate a very basic hypothesis relating to the likelihood of a woman versus a man to be a carer in the South African adult population.

The association of increased chronic disease, frailty and disability with increased age, and the follow-on association of increased care needs, have contributed to stereotyping older persons as recipients of care. A few empirical studies, however, have shown that older persons are not only recipients of care, but also caregivers. In this light, the thesis study quantitatively examines older persons' contributions in providing informal in the context of frailty, disability or ill-health.

Chapter 4

METHODOLOGY

4.1 METHODOLOGY OF THE THESIS STUDY

4.1.1 Type of study and source of data

The thesis study is based on secondary data analysis of a quantitative omnibus-type cross-sectional household survey which included a question on informal caregiving. The survey was conducted in 2000 by the Human Sciences Research Council (HSRC) among a representative sample of the free-living public 18 years or older. A number of variables with quantitative data on demographic, socio-economic and household information related to the respondents, were extracted from the original HSRC dataset and utilized in the analysis.

4.1.2 Sampling, data collection, data processing

As data were merely extracted from the above-mentioned survey, information about sampling, data collection and data processing are not discussed here. The methods related to these processes in the original HSRC study are described in Section 4.2.

4.1.3 Reliability and validity of the data

Purchasing participation space for one question in an omnibus survey poses problems in establishing reliability, or the likelihood of obtaining the same answer when the same issue was to be measured again. No validity-testing was done prior to the survey, yielding a shortcoming as discussed in Chapter 6. However, in an attempt to ensure that the question would measure what it was meant to measure, extensive consultation was done with local experts and service providers in the field of caregiving, as well as with an international expert who has worked on similar studies in the United Kingdom.

4.1.4 Hypotheses

While the literature from developed countries demonstrates specialized work around hypothesis testing relating to psychological, sociological and financial theories, the hypotheses formulated for this study relate to basic issues in the subject of informal caregiving, i.e. gender and age. The first hypothesis was informed by feminist theory and aimed to investigate whether women were more likely than men to be an informal carer in the South African society. The second hypothesis was formulated as a response to the student's observation in a few empirical studies that older persons were not only care recipients, but also caregivers. The following two hypotheses were formulated:

> **Hypothesis 1:**
>
> *Women are more likely than men to be an informal carer in the South African society.*
>
> **Hypothesis 2:**
>
> *Older and younger persons are equally likely to be informal carers in the South African society.*

More variables were examined in relation to informal caregiving, e.g. geographic residence (province), population group, employment, income and education, but no hypotheses were formulated around these variables. Province and population group were included in the analysis as they were variables used in the sample stratification. The other variables were used in a descriptive fashion so as to explore the data set, and it is hoped that further research in the field would examine them in further analyses including hypotheses testing.

4.1.5 Definition of the variable used in the study

Reviewing the literature makes it clear that globally there is no generally-accepted or standard definition of “informal care/r”. In consultation with service providers and experts in the field, it was decided to include in the definition a time and setting restriction, as well as three specific care-requiring conditions—aspects that were successfully applied and researched in a definition used previously by the Carers National Association in the United Kingdom. The definition is embodied in the following question which was asked to the survey participants:

> “D*o you personally provide care for at least two hours per day for someone in your household who—owing to frailty, disability or ill-health—cannot manage without help?*”

As indicated in section 1.1 in the Introduction chapter, such care would be that which is provided to a child or adult who need assistance beyond that customarily needed for a healthy, able-bodied person.

4.1.6 Analysis

Basic univariate analyses, using frequencies and cross-tabulations, were conducted with SPSS to present a descriptive demographic and socio-economic profile of both the sample participants and the informal carers who participated in the study. To investigate sex and age differentials within these profiles, multivariate cross-tabulations were constructed, and significance levels at alpha < 0.05 were computed with the Pearson Chi-square statistic.

Logistic regression analysis, using the prevalence of caregiving as the dependent variable, and selected categorical demographic and socio-economic characteristics as independent variables, were conducted to identify the odds of a person being a carer. Being a carer, or not, has been used as a dichotomous variable (0 = being not a carer; 1 = being a carer). Adjusted odds ratios, 95% confidence intervals, and significance levels were calculated for the dependent variable in relation to each of the following:

- age [18-59 years (reference group), ≥ 60 years];
- sex [male (reference group), female];
- population group sex [African Black (reference group), Coloured, Asian, White];
- province of residence sex [Western Cape (reference group), Eastern Cape, Northern Cape, Free State, KwaZulu-Natal, North West, Gauteng, Mpumalanga, Limpopo]; and
- area of residence [metropolitan (reference group), urban, rural).

Stata Statistical Software Release 8.0 was used for the logistic regression analyses. This programme was used to allow for the effects of the complex survey design, using the survey command ‘svylogit’ to estimate the logistic regression model. ‘Province’ was used as the stratification variable, and the cluster design and weighting factors were incorporated in the model.

The regression model demonstrated rather weak prediction potential, and the purpose of the regression exercise henceforth was not to predict when a person would be a carer, nor to establish those variables that would best predict a person being a carer, but to assist in testing the hypotheses through ascertaining the significance of associations while adjusting for the effects of other variables. Stepwise regression has not been used, but rather a model that includes all the variables at once, allowing testing of the hypotheses while adjusting for the effects of other variables.

4.1.7 Ethical considerations

The thesis study was based on selected data extracted from the original HSRC dataset, and no new data were collected, nor were any new human field contacts made. The original study was conducted under the ethical research codes of the HSRC, has not involved animals, and no clinical measurements were taken. More specific ethical issues related to the HSRC study are available in Section 4.2.

Confidentiality of the data was maintained in this analysis, and no details extracted from the original data set have been used in a manner that may expose a study participant's identity.

4.2 METHODOLOGY OF THE HSRC OMNIBUS SURVEY

4.2.1 Introduction

The Human Sciences Research Council (HSRC) has for over 20 years conducted national surveys of public opinion, investigating a wide range of topics, including perceptions of national priorities, satisfaction with service delivery, migration tendencies, and opinions about various national institutions such as the media, police and the courts. Additionally, questions from a range of paying clients are included into these studies. In view of limited funds and the sample size required to facilitate generalisation to the South African adult population, it was considered expedient and affordable to utilise one of these surveys to investigate informal care in South Africa.

Full methodological details are available elsewhere (Rule, 2001), but selected issues will be highlighted below.

4.2.2 Type of study and type of data

A cross-sectional national household survey was conducted. Closed questions were administered by the interviewers to provide quantitative information on the topics included in the survey. Additional quantitative data, such as demographic and socio-economic data, were collected.

4.2.3 Sampling

The universe of the sample design constituted free-living South African adults 18 years or older. A national multi-stage stratified area cluster probability sample was drawn, using enumerator areas as a sampling frame for the clusters. A sample of 2704 persons, selected throughout the country in clusters of eight and situated in 338 census enumerator areas, were included. The selection process commenced with the stratification of enumerator areas by province, and a minimum of 30 enumerator areas were selected randomly to ensure that the least-populated provinces were adequately represented to discern trends at provincial level. Enumerator areas with know Indian majorities were over-sampled to ensure adequate representation of the Indian population in the final sample (Rule, 2001: 1-2)

In the penultimate sampling stage, census enumerator areas were used as clusters from which households were systematically drawn with equal probability. At the households, respondents were randomly selected from qualifying household members with the use of a randomised kish grid.

4.2.4 Data collection and processing

4.2.4.1 Research instrument

An interviewer-administered paper-copy questionnaire was used to collect data in the field. The questionnaire contained 34 pages of questions, divided into different topics. The student was responsible for negotiating space in the questionnaire, and wording the carer question for inclusion. The carer question was: "Do you personally provide care for at least two hours per day for someone in your household who—owing to frailty, disability or ill-health—cannot manage without help?" This was translated into isiXhosa on the questionnaire too.

4.2.4.2 Fieldwork

Fieldwork teams were recruited in the provinces, and training workshops were conducted to provide prospective fieldworkers with the necessary information and training on sampling of household members and completion of the questionnaires. The questions was in both English and isiXhosa, but additional attention was given to certain concepts to ensure correct understanding in the interviewees if the need arose to translate into a South African language other than English. Data were collected during individual face-to-face interviews, ranging in duration from 60 to 90 minutes each.

4.2.4.3 Quality control and data processing

Fieldwork team leaders checked the filled questionnaires for completeness and correctness of sub-question procedures. The data were then captured at the HSRC's data-capturing division, and prepared for analysis according to specific data-editing procedures (Table 4.1).

4.2.4.4 Sample realization

Due to access difficulties in the field, 2611, in stead of 2704, respondents were interviewed in the study, which means a response rate of 96.6%. The spread of the realised sample was however sufficiently wide to facilitate statistical generalisations about opinions prevailing among persons in each of the population groups and provinces (Rule, 2001).

Table 4.1: Realisation of survey sample by province and population group

Province	African Blacks	Coloureds	Asians	Whites	Total
Western Cape	48	141	17	55	262
Eastern Cape	212	16	0	49	277
Northern Cape	98	99	1	55	253
Free State	204	3	0	38	245
KwaZulu-Natal	290	11	112	19	432
North West	174	1	7	36	218
Gauteng	216	24	75	115	430
Mpumalanga	212	9	2	24	247
Limpopo	225	3	0	19	247
Total	1679	307	214	410	2611

Source: Rule, 2001: 2.

4.2.5 Weighting

For the analysis, the sample was weighted to replicate the national population 18 years or older in terms of province, population group, sex and level of education attained. The weighted sample distribution by province and population group is presented in Table 4.2.

Table 4.2: Weighted sample distribution by province and population group

Province	African Blacks %	Coloureds %	Asians %	Whites %	Total %
Western Cape	2.3	5.6	0.2	2.6	10.7
Eastern Cape	12.1	0.5	0.0	1.0	13.6
Northern Cape	1.1	1.3	0.0	0.5	2.9
Free State	5.8	0.1	0.0	0.8	6.7
KwaZulu-Natal	16.0	0.2	2.3	1.7	20.1
North West	7.7	0.1	0.1	0.7	8.5
Gauteng	14.7	0.5	0.4	4.8	20.4
Mpumalanga	6.0	0.2	0.0	0.5	6.7
Limpopo	10.0	0.1	0.0	0.3	10.3
Total	75.5	8.5	3.0	13.0	100.0

Source: Rule, 2001: 2.

4.2.6 Ethical considerations

The survey was conducted under the research ethical codes of the HSRC. Verbal consent was obtained from the prospective respondents, who were informed about the purpose of the survey and the content of the questionnaire. Prospective interviewees were assured that participation was voluntarily, that there would be no consequences if they refused to participate, and that they were free to withdraw during the interview without supplying any reason. Confidentiality of the information supplied by interviewees was assured, and prospective respondents were informed that any information provided by them would not be recognizable as belonging to them when included in a report.

Chapter 5

Findings

5.1 INTRODUCTION

This chapter consists of four main sections. Section 5.2, in addition to Section 4.2.4.4, describes relevant characteristics of the survey sample from which data has been extracted for the thesis study. Using the survey data related to informal carers, Section 5.3 sketches a demographic and socio-economic profile of informal carers and shows the proportions of carers with access to selected household amenities. In Section 5.4, the focus shifts from describing informal carers as a group, to describing the South African population in terms of the prevalence of caregiving in the country, providing information about prevalence levels in a number of sub-populations. In Section 5.5, logistic regression was used to estimate the odds of someone being a carer in relation to sex and age. As will be indicated in this last section, a good predictive model could not be found.

5.2 CHARACTERISTICS OF THE SAMPLE

From the national sample of 2704 persons 18 years or older,[1] a total of 2611 respondents participated in the survey, implying a response rate of 96.6%. The sample comprised all provinces and population groups,[2] of which the categories have been realised as indicated in Chapter 4, Table 4.1. For the analysis, the

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[1] For ease of reference, the population 18 years or older will be referred to as 'adults'.

[2] The population group classification in the thesis is in accordance with the Population Registration Act of 1950. This classification has been used to highlight issues that may portray effects of historical disparities, and the student do not subscribe to this classification for another purpose.

sample was weighted to replicate the national population 18 years or older in terms of province, population group, sex and level of education attained. The weighted sample distribution by province and population group is presented in Chapter 4, Table 4.2. The basic demographic characteristics of the study participants in the sample are reflected in Table 5.1 below.

Table 5.1: Selected demographic characteristics of the sample

Demographic Variables	Valid % (weighted)	N (unweighted)	Missing Number (%)
Age			
18-19	6.5	172	
20-29	22.6	654	
30-39	23.2	645	
40-49	18.5	500	
50-59	13.5	305	
60-69	9.2	191	
70+	6.5	136	
Total	**100**	**2603**	**8 (0.3%)**
Sex			
Male	45.7	1098	
Female	54.3	1511	
Total	**100**	**2609**	**2 (0.08%)**
Population group			
Black	75.5	1679	
Coloured	8.5	307	
Indian	3.0	214	
White	13.0	410	
Total	**100**	**2610**	**1 (0.04%)**
Province			
Western Cape	10.8	262	
Eastern Cape	13.6	277	
Northern Cape	2.9	253	
Free State	6.7	245	
KwaZulu-Natal	20.1	432	
North West	8.5	218	
Gauteng	20.4	430	
Mpumalanga	6.7	247	
Limpopo	10.3	247	
Total	**100**	**2611**	**0**

Demographic Variables	Valid % (weighted)	N (unweighted)	Missing Number (%)
Area:			
Metro	27.5	628	
Urban	38.0	1244	
Rural	34.5	739	
Total	**100**	**2611**	**0**

5.3 PROFILE OF CARERS

To replicate the South African population 18 years or older, the sample was weighted as indicated before, and the survey showed that, in 2000, 26.9% of the population were caregivers according to the definition used. This implies that an estimated 7.4 million persons in the South African population 18 years or older had informal caregiving responsibilities in the year 2000[3]. Tables 5.2, 5.3 and 5.4, respectively, provide selected demographic, socio-economic and household characteristics of the carers in the thesis study.

5.3.1 Selected demographic characteristics

The median age of male carers in the sample was 38 years, and that of female carers 37 years. The weighted data in Table 5.2 show that the largest proportions of carers in this sample were in the age groups 30-39 and 20-29 years, totalling 47%. Carers 60 years or older,[4] made up 18% of all carers, translating into an estimated 1.3 million older persons with carer responsibilities in their household.[3] The carers in the sample were mainly women, constituting 59% of all carers.

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[3] This number has been arrived at using data from the 2001 Census (Statistics South Africa, 2003).

[4] Persons 60 years or older, and persons younger than 60 years, respectively, will be referred to in the text as "older persons" or "older carers", and "younger persons" or "younger carers".

These patterns, as expected, are similar to the distribution of the sample population.

Table 5.2: Selected demographic characteristics of carers

Demographic variables	% (weighted)	N (unweighted)
Age		
18-19	7.8	44
20-29	22.8	149
30-39	23.8	151
40-49	14.9	96
50-59	13.1	69
60-69	9.4	43
70+	8.1	40
Total	100	592
Sex		
Male	40.8	225
Female	59.2	367
Total	100	592
Total	**100**	**592**

5.3.2 Selected socio-economic characteristics

Table 5.3 shows that about half of the carers in the sample were married or cohabiting, and that the majority of the single carers were never married. While the majority had either a secondary or primary school education, 13% had no formal school education, and very few had tertiary qualifications. Less than one-third were employed, 41% unemployed, and the remainder were pensioners, students or homemakers. Of the unemployed carers, 80% were looking for a job (data not presented here). A large proportion, almost half of the carers in the sample, had no income at the time of the survey, and over a third had a reported gross personal income of less than R1250,00 per month.

Table 5.3: Selected socio-economic characteristics of carers

Socio-economic variables	% (weighted)	N (unweighted)
Marital status		
Married	47.4	270
Living together	3.7	24
Divorced	2.6	16
Widowed	6.6	35
Never married	38.5	240
Other	1.2	6
Total	100	591
Educational level		
None	12.5	55
Primary school	32.2	144
Secondary school	47.2	317
Diploma	6.5	61
Degree	1.6	15
Total	100	592
Employment status		
Unemployed	40.6	232
Informal sector	4.0	23
Pensioner	17.1	88
Housewife	3.1	25
Student	8.6	52
Full-time employed	18.7	133
Part-time employed	7.9	37
Other	0.2	2
Total	100	592
Gross personal income per month		
None	48.2	219
<R1250	36.5	145
>=R1250	15.3	88
Total	**100**	**452**

5.3.3 Access to selected household amenities

Some household amenities have the potential to facilitate an enhanced caregiving environment for both the carer and care recipient, or to ease a carer’s caregiving tasks. A selected number of such amenities were retrieved from the dataset to assess the carers’ access to them. Table 5.4 shows that relatively large proportions of carers had access to electricity (72%) and a fridge or freezer (59%), but less than half had access to a flush toilet. About one-quarter of the carers had access to a telephone, about one-fifth to hot running water, and even lower proportions had access to a motor vehicle (17%), washing machine (16%), cell phone (13%), or domestic aide (9%).

Table 5.4: Percentage carers with access to selected household resources

Household amenities	% (weighted)	N* (unweighted)
Flush toilet	44.7	588
Hot running water	21.2	590
Electricity	72.3	591
Working telephone	25.5	585
Cell phone	12.6	580
Motor vehicle	17.0	588
Domestic aide	8.7	588
Washing machine	15.6	572
Fridge/freezer	59.4	592

* Numbers differ because of missing values.

5.4 PREVALENCE OF CARERS IN THE SOUTH AFRICAN POPULATION

While a demographic and socio-economic profile of the participating carers was sketched in the previous section, in this section the prevalence of caring will be examined by selected demographic and socio-economic characteristics of the country's adult population. It was indicated in paragraph 5.3 that 27% of the sample reported to be carers. In Tables 5.5 and 5.6 a number of Chi-square goodness-of-fit tests were applied at a 5% level of significance by using the following hypotheses:

H_0: $p_1 = p_2 = p_3 \ldots\ldots = p_n = 0.27$

H_1: At least two of the proportions are not equal to 0.27

where p_i is the proportion of the i^{th} group who are carers.

5.4.1 Prevalence of carers in the population by demographic characteristics

(a) Age and sex

Given the national representativeness of the sample, the results from the study show that, in 2000, about a third of South African adults 70 years or older had carer responsibilities, which is the highest proportion among the 10-year age groups. The proportion decreased to about a quarter in most other age groups, but the difference between age groups was not significant ($p = 0.246$). Neither was a significant difference found between the age groups when considering males ($p = 0.493$) and females ($p = 0.366$) separately.

Of South African adult women, 29% were carers, compared to less than a quarter of adult men. This indicates a significant difference between men and women in relation to having informal caregiving responsibilities ($p = 0.025$). Considering older and younger carers separately, however, the difference was not significant, possibly due to the smaller sample size in the relevant sub-entities.

(b) Population group, province and area

Table 5.5 illustrates a significant difference ($p < 0.001$) among the population groups with a much higher proportion of Blacks (31%) being carers than any other population group. A significant difference among population groups was also present when looking at caring within males and females separately ($p < 0.001$). While a significant difference in the prevalence of informal care between population groups was observed among younger persons ($p = < 0.001$), the prevalence levels in older persons reflected insignificant differences ($p = 0.345$) as about 30% of Black, Coloured and Indian older people were carers, compared to about 20% of White older people.

Column (5) shows a significant difference ($p < 0.001$) among the provinces, the proportions ranging from about 15% in the Western Cape and Free State, to about a third of the adult population in KwaZulu-Natal and Limpopo. Similarly, significance in difference was found among the provinces when considering caring responsibilities in males ($p < 0.001$) and females ($p < 0.001$), as well as younger ($p < 0.001$) and older carers ($p = 0.048$), separately—albeit marginally significant in older carers.

A significant difference was found in the prevalence levels among rural, metropolitan and urban areas ($p < 0.001$), a pattern that is repeated in both younger ($p < 0.001$) and older ($p = 0.003$), as well as male ($p < 0.001$) and female ($p < 0.001$) carers.

Table 5.5: Percentage of South Africans 18 years or older who were carers by selected demographic characteristics, by sex and age

Demographic characteristics	% Carers					
	Male (weighted)	**Female (weighted)**	**Age <60 (weighted)**	**Age ≥60 (weighted)**	**Total (weighted)**	**Number (unweighted)**
Age						
18-19	30.4	34.5	-	-	32.5	172
20-29	26.0	28.3	-	-	27.3	654
30-39	22.0	32.1	-	-	27.7	645
40-49	18.4	24.8	-	-	21.7	500
50-59	25.8	26.4	-	-	26.1	305
60-69	23.7	30.8	-	-	27.6	191
70+	34.0	33.0	-	-	33.4	136
	($p = 0.493$)	($p = 0.366$)			($p = 0.246$)	(2603)
Sex						
Male	-	-	23.5	27.4	24.0	1098
Female	-	-	28.8	31.8	29.2	1511
			($p = 0.061$)	($p = 0.172$)	($p = 0.025$)	(2609)
Population group						
Black	28.3	33.1	30.8	31.3	30.9	1679
Coloured	10.4	22.7	15.2	29.2	17.3	307
Indian	16.1	20.2	16.9	28.8	18.2	214
White	10.2	12.8	10.6	19.9	11.5	410
	($p < 0.001$)	($p < 0.001$)	($p < 0.001$)	($p = 0.345$)	($p < 0.001$)	(2610)
Province						
Western Cape	9.9	21.4	14.4	25.8	15.9	262
Eastern Cape	19.0	27.3	22.3	29.8	23.9	277
Northern Cape	17.4	15.6	16.9	12.0	16.3	253
Free State	13.7	15.0	15.7	6.7	14.4	245
KwaZulu-Natal	37.3	35.3	36.7	33.0	36.2	432
North West	16.5	28.6	24.0	18.8	22.9	218
Gauteng	22.7	35.8	27.1	46.9	29.2	430
Mpumalanga	35.4	23.0	29.4	24.8	28.7	247
Limpopo	31.4	33.0	31.4	35.9	32.4	247
	($p < 0.001$)	($p < 0.001$)	($p < 0.001$)	($p = 0.048$)	($p < 0.001$)	(2611)
Area						
Metro	20.3	30.8	23.2	44.4	25.8	628
Urban	18.1	22.8	21.2	17.1	20.6	1244
Rural	35.0	34.4	35.1	32.8	34.6	739
	($p < 0.001$)	($p < 0.001$)	($p < 0.001$)	($p = 0.003$)	($p < 0.001$)	(2611)
Total	**24.0**	**29.2**	**26.4**	**30.0**	**26.9**	**2611**

\- Category not applicable.

5.4.2 Prevalence of carers by socio-economic characteristics

(a) Marital status, education, employment, income

Table 5.6 below indicates that 29% of never-married adults were carers, closely followed by 28% of cohabiting and 26% of married adults. However, no significant difference in the extent of caregiving was found among persons with different marital statuses ($p = 0.137$).

A slightly significant ($p = 0.033$) difference was found with respect to the level of education. The proportion of adults with caring responsibilities decreased as the level of education among them increased, ranging from a third of those with no education to 13% of those with a degree. The difference by level of education was not significant in men and women, or in older and younger carers separately (see Table 5.6). This may be due to the smaller sample sizes in the sub-groups.

Close to 39% of persons working in the informal sector and about 30% of unemployed persons, pensioners and students, each, were caring for another person. The proportions of housewives and employed persons with carer responsibilities were considerably lower, and it became clear that employment status played a significant role in whether someone was a carer, or not ($p < 0.001$). Considering males ($p < 0.001$) and females ($p = 0.020$) separately, as well as younger persons ($p < 0.001$), the significance in difference remains with regard to employment status.

Table 5.6 further shows a significant difference among persons within the specified categories of gross personal monthly income (p = 0.003), a pattern repeated in males (p = 0.020) and younger persons (p = 0.004), but not in females (p = 0.161) and older persons (p = 0.896).

Table 5.6: Percentage of South Africans 18 years or older who were carers by selected socio-economic characteristics, by sex and age

Socio-economic Variables	**% Carers**					
	Male (weighted)	**Female (weighted)**	**Age <60 (weighted)**	**Age ≥60 (weighted)**	**Total (weighted)**	**Number (unweighted)**
Marital status						
Married	22.1	30.4	25.3	31.1	26.4	1265
Living together	20.8	36.5	28.9	..	28.3	92
Divorced	18.7	22.2	24.6	..	20.6	79
Widowed	20.4	23.1	23.4	20.9	22.4	192
Never married	28.1	30.1	28.2	55.4	29.2	944
Other	(28.0)	(23.5)	21.9	(71.4)	25.1	26
	(p = 0.175)	(p = 0.235)	(p = 0.159)	(p = 0.030)	(p = 0.137)	(2598)
Educational level						
None	31.4	33.8	33.6	31.7	32.8	191
Primary school	24.8	30.1	26.7	31.1	27.7	600
Secondary school	23.4	30.1	27.1	26.8	27.0	1399
Diploma	23.3	19.6	20.9	[34.8]	21.3	310
Degree	12.0	16.2	13.6	[14.3]	13.4	105
	(p = 0.364)	(p = 0.092)	(p = 0.127)	(p = 0.596*)	(p = 0.033)	(2605)
Employment status						
Unemployed	28.5	31.4	30.2	25.5	30.0	871
Informal sector	42.4	34.3	34.5	[77.9]	38.5	78
Pensioner	28.4	32.1	31.9	30.4	30.7	323
Housewife	-	14.9	15.9	[43.7]	17.5	161
Student	34.2	24.6	29.9	[17.4]	29.7	215
Full-time employed	14.7	28.4	20.4	[19.3]	20.1	765
Part-time employed	19.6	32.3	25.8	..	25.4	190
Other	(53.2)	(18.1)	(44.4)	..	(44.4)	4
	(p < 0.001)	(p = 0.020)	(p < 0.001)	(p = 0.643*)	(p < 0.001)	(2607)

Socio-economic Variables	**% Carers**					
	Male (weighted)	**Female (weighted)**	**Age <60 (weighted)**	**Age ≥60 (weighted)**	**Total (weighted)**	**Number (unweighted)**
Gross personal income / month						
None	29.3	28.3	28.8	26.0	28.7	882
<R1250	23.8	29.3	25.3	29.2	27.0	590
>=R1250	17.3	24.4	19.4	28.3	20.1	507
	(p = 0.020)	(p = 0.161)	(p = 0.004)	(p = 0.896)	(p = 0.003)	(1979)
Total	**24.0**	**29.2**	**26.4**	**30.0**	**26.9**	**2611**

( ) Percentage values in parenthesis—but not the p-values—are unreliable as they are based on cell values with an expected count less than 5.
* P-value calculated on combined values in square brackets. The categories were combined as, separately, they were too small for statistical testing.
[ ] Values in square brackets were combined when calculating the p-value. See * directly above.
.. No data for the particular entry.

5.5 Logistic regression of the odds of caregiving

In addition to presenting a descriptive demographic and socio-economic profile of informal carers in South Africa, the hypotheses in the thesis additionally sought to investigate sex and age differentials related to caregiving, specifically to examine whether men and women are equally likely to be informal carers, and whether older (≥ 60 years) and younger (18-59 years) persons are equally likely to be informal carers. This section presents the results of multivariate analyses, providing information on the relative importance of selected demographic characteristics in the likelihood of being a carer. Logistic regression analysis, using the prevalence of caregiving as the dependent variable, and selected categorical demographic characteristics as independent variables, were conducted to identify the odds of a man versus a women being a carer, and the odds of an older versus a younger person being a carer.

Early in the regression analyses, it was clear that there is limited potential for prediction in the model. This was ascertained through the very low value of the multiple correlation coefficient, R^2, which represents the proportion of the variance in caregiving that could be explained by the particular variables combined in the model. By incorporating the complex sample design in the regression analysis, no straight-forward measure of the multiple correlation or goodness of fit was possible. But, when fitting the model without controlling for the design effects, it was possible to obtain a Pseudo R^2 value, which was 0.0516.[5] This value indicates that the model has very limited potential for prediction, and that large influences on the prevalence of caregiving are mediated through factors other than those included in the model. It was hence clear that the model explains a negligible part of the variance, and that it would be an inadequate prediction model.

While acknowledging the limited prediction value of the model, is was nonetheless thought useful to utilize the odds ratios generated in the model to further examine the hypotheses which seek to investigate whether men and women, and older and younger carers are equally likely to be a carer in the South African society. For this purpose, Table 5.10 below was constructed from the full logistic regression model in which the sample design was controlled for.

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[5] For complex survey data like those used for the thesis, the weighted 'likelihood' is not the distribution function for the sample, and therefore it is not a true likelihood. It is hence referred to as a "pseudo" likelihood (StataCorp, 2003).

Table 5.7: Logistic regression of the odds of caregiving on age, sex, population group, province, and geographic area.

Variable	Categories	Odds ratio	95% CI for odds ratio	p-value
Sex	**Male**	1	Referent	
	Female	1.297	1.036 – 1.623	0.023
Age	**< 60 years**	1	Referent	
	≥ 60 years	1.180	0.913 – 1.525	0.206
Population group	**Black**	1	Referent	
	Coloured	0.651	0.370 – 1.145	0.136
	Asian	0.426	0.225 – 0.806	0.009
	White	0.330	0.180 – 0.604	<0.001
Province	**Western Cape**	1	Referent	
	Eastern Cape	0.897	0.395 – 2.036	0.795
	Northern Cape	0.873	0.378 – 2.017	0.749
	Free State	0.599	0.227 – 1.578	0.298
	KwaZulu-Natal	1.841	0.844 – 4.015	0.124
	North West	0.954	0.388 – 2.348	0.918
	Gauteng	1.746	0.771 – 3.954	0.180
	Mpumalanga	1.233	0.527 – 2.883	0.628
	Limpopo	1.236	0.535 – 2.853	0.619
Area	**Metro**	1	Referent	
	Urban	0.893	0.525 – 1.519	0.676
	Rural	1.376	0.747 – 2.535	0.304

Adjusting for age, population group, province and geographic area, a significant sex difference was shown, in that the odds for women was 30% higher than that for men to be a carer (p = 0.023). This offers support for Hypothesis 1 which suggests that women are more likely than men to be an informal carer.

Adjusting for sex, population group, province and geographic area, the model shows that the odds of being a carer in older persons was 1.180 that of the odds in younger persons. It was hence a slightly higher odds in persons 60 years or older, but not statistically significant (p = 0.206). This suggests that caregiving is as prevalent among older persons as it is among younger ones, offering support for Hypothesis 2 in which it is argued that older and younger persons are equally likely to be a carer, and confirming the finding in other empirical works that older persons are indeed also caregivers, not only care recipients.

The analysis also indicates that African Blacks had significantly higher odds of having carer responsibilities compared to Asians and Whites. Among the provinces, persons in KwaZulu-Natal, Gauteng, Limpopo and Mpumalanga were more likely to be a carer relative to those living in the Western Cape, and rural-living persons were more likely to have carer responsibilities than those living in a metropolitan area (see Table 5.7).

Chapter 6

Discussion, Conclusions and Recommendations

6.1 DISCUSSION

6.1.1 Need for informal care in South Africa

The impact of demographic and epidemiological change in South Africa, through the simultaneous effects of population ageing and an intensified, quadruple burden of disease, have brought about changes in the health profile of the population. In turn, these changes have affected an increased need for care in the country. In the presence of this increased demand for care, evidence exists that formal public health care services fall short of providing adequate and satisfactory care to those who need care, while, at the same time, spiralling private health care costs place private health services beyond the financial reach of the majority of the population.

There is evidence that the severe AIDS epidemic, in particular, has contributed extensively to the burden of disease and the demand for care. Due to the magnitude in the number of AIDS-sick persons, and the drawn-out nature of AIDS morbidity, it is likely that the need for care has intensified over the past five years. The fluctuating functional ability of patients during the symptomatic phase, and the particular manifestations and progression of the disease which often do not fit into conventional curative, chronic or palliative care models, complicate caregiving to persons with AIDS in the formal sector, thereby implying an increased need for informal care in the home setting.

Despite the abovementioned situations pointing to an increased demand for informal care, no research has yet been done to assess the national extent of informal care in South Africa, or to present a profile of such carers from a representative sample. The thesis study offers an opportunity to bridge the gap in information on the national extent of informal care, and to present a representative socio-demographic profile of informal carers in the country.

6.1.2 Extent of informal caregiving

The study has found that informal caregiving is widespread in South Africa with 27% of the adult population, or an estimated 7.4 million adults, reporting to be an informal carer according to the definition used. There is no internationally-accepted uniform definition of informal care/r, and as definitions range from very broad descriptions to very restricted or detailed ones, caution needs to be exercised when comparing numbers and proportions across populations (Pijl, 2003: 28). However, a definition of informal carers that compares fairly well with the definition used in the thesis study, is one used in Great Britain's 2000 General Household Survey (GHS)[1]. South Africa's national figure, 27%, is considerably higher than Great Britain's 16% in its population 16 years or older (Maher & Green, 2002). When comparing the same age cut-off points for the two societies, South Africa still had a higher proportion of carers in its 18+ population (27%) compared to Great Britain's 19% of its 18+ population (Stuchbury, 2003). Some regional proportions in the Great Britain study, such as those in Wales and the North East region, reached as high as 18% and 20%, respectively, which, in turn are higher than the 16% found in the provincial populations of the Western and Northern Cape each (Maher & Green, 2002: 8)

Considerable variation exists in national prevalence figures from studies conducted in some countries around the turn of the century. The following examples show such variation, while at the same time highlight the previously-raised concern about differences in defining the concept ‘informal care/r’:

- nearly 11% of the Canadian population 15 years or older provided informal care during the 12 months preceding the survey, to one or more persons 65 years+ with a long-term health problem or physical limitation (Keating *et al*., 1999: 34);
- over 23% of all United States households had a carer, 18 years or older, providing care at the time of the survey, or at some point in the 12 months prior to the survey, to a relative or friend who is aged 50 years or older (National Alliance for Caregiving (NAC) & American Association of Retired Persons (AARP), 1997: 8);
- in the Netherlands, 11% of the adult population are informal carers[2] (Pijl, 2003: 28);
- depending on geographic regions, between 3% and 10% of the Irish population are informal carers (Pijl, 2003: 28).

South Africa’s higher prevalence may be related to the country’s particularly intense and diverse burden of disease which has changed from a characteristic developing country dual profile of communicable and emerging non-communicable conditions during the 1980s (Bradshaw, Dorrington & Sitas, 1992); to a triple burden of disease with the added burden of high injury rates during the 1990s

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[1] Carers were defined as “people who were looking after, or providing some regular service for, a sick, disabled or elderly person living in their own or another household” (Maher & Green, 2002: x). The GHS was conducted among persons 16 years or older, and all types of caring tasks for any number of hours were included.

[2] The definition used for ‘informal care(r)’, was not supplied in Pijl (2003).

(Butchart & Peden 1997); building up into a quadruple burden of disease, with the major addition of HIV/AIDS to a combination of persistent pre-transitional conditions related to under-development and poverty, mounting non-communicable conditions traditionally associated with a Western lifestyle, and excessively high rates of injuries.

The higher prevalence levels locally may also relate to issues of poverty and development and the consequent differences regarding access to and affordability of formal health care services or access to formal home care services. Another potential reason for the higher levels may relate to a methodological shortcoming of the study, namely that the carer question was not validated prior to the fieldwork. Although unpaid care is difficult to measure, different alternative methods of data collection, including observation, an activity log, a time diary, and an activity matrix may prove useful in validating such a question in future.

6.1.3 Profile of carers

(a) Sex

Consistent with findings locally and in other countries, this study has shown higher female (59%) than male proportions of carers. Two more similar studies in South Africa, each conducted in smaller, non-representative samples, have found that the majority of the carers were women (Akintola, 2004; Joubert *et al*., 2002). Higher proportions of female carers were also reported in the above-mentioned Great Britain and Canadian studies, both finding that 61% of their carers were female (Maher & Green, 2002: 8; Keating *et al*., 1999: 34). National studies in the United States and Australia have shown even higher proportions of female carers, that is, respectively, 73% and 70% (NAC & AARP, 1997: 8; Australian Bureau of Statistics, 1999a, as cited in Jenkins *et al*., 2003: 1).

As the survey instrument relied on the self-identification of carers, it may have been possible, as cautioned by Keating *et al*. (1999: 28), that some female study participants did not consider certain tasks as ‘caregiving’, but rather as tasks that are part of their usual domestic or parenting role. On the other hand, household chores or routine parenting tasks may have been considered by some male study participants as informal care tasks. Such a scenario may have presented with even larger sex differentials than currently reported in the results. Indeed, South Africa’s first time-use survey (Statistics South Africa, 2001: 109), using a 24-hour diary technique, indicated that of those respondents who engaged in caregiving activities that are generally comparable to those in the thesis study, 82% were female.

Considering the prevalence findings, the study showed that women were significantly more likely than men to have a carer role. Female proportions of carers were consistently larger than male’s within the population groups, and, except in the 70+ group,[3] also so in all the specified age groups. After controlling for the complex sample design, and adjusting for relevant demographic characteristics, women still were significantly more likely than men to have caregiving responsibilities.

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[3] This exception may be a reflection of the longer life expectancy in women than in men, resulting in relatively higher numbers of older women in need of care, receiving spousal care from a relatively higher number of men in this older age group.

(b) Age

Carers were broadly and fairly-equally distributed across the population in terms of their age, with slightly larger proportions in the youngest (18–19) and oldest (70+) age groups. Considering the slightly higher likelihood in older carers (60 years+) compared to younger carers (< 60 years), the study results support the findings of a few other local and international studies showing that older persons are not only recipients of care, but also providers thereof. The higher likelihood in older persons may reflect their carer role in the particularly large burden of injury and AIDS disease in young adults, their role in caring for AIDS-infected and –affected grandchildren, or their role in caring for mentally restrained or physically disabled grandchildren whose parents have found employment and residence elsewhere. It may also be a reflection of the de-institutionalizing policies affecting frail older persons, or the insufficient formal public services available to older persons, or the reported dissatisfaction with such services in older persons, compelling increased spousal, partner or peer care among older persons themselves.

(c) Population group

The prevalence of informal caregiving differed significantly across the population groups with the largest prevalence in African Blacks, being about double the rate in the remaining population groups. Very high prevalence rates were found in persons speaking isiZulu, Tshivenda, Xitsonga and Siswati most often at home. The differences among population groups may be accounted for by various explanations, including differences in burden of disease and disability per population group; different cultural customs and preferences in looking after frail, sick or disabled household members; different living arrangements among population groups; differences in access to formal health care services; and differences in the buying power of formal health care.

(d) Geographic residence

Significant differences were demonstrated in the prevalence levels among the nine provinces, with the north-eastern provinces of KwaZulu-Natal, Gauteng, Limpopo and Mpumalanga reflecting the most extensive demand for informal carer services. Rural areas showed a greater prevalence compared to urban and metropolitan areas. These differences may be attributed, among other, to geographic differences in access to formal health care services; differences in the availability of institutional care; differences in burden of disease and disability; and differences in employment rate which may impact on the availability of caregivers.

(e) Socio-economic characteristics

The prevalence of caregiving was significantly associated with participants' level of educational attainment, employment status and their gross personal income per month. The inter-relatedness of these independent variables complicates explanations, but, generally, lower income, lower educational levels, unemployment and informal employment were associated with higher prevalence of caregiving. The data unfortunately do not allow investigation of these relationships to establish, for example, whether people are carers because of unemployment, or whether they are unemployed because of their carer responsibilities.

(f) Access to amenities

Except for relatively good access to electricity and a fridge/freezer, access to the other amenities investigated in the study was rather poor. Both carer and care recipient have specific needs and requirements in a caregiving environment, and access to certain household amenities have the potential to ease carers' tasks, or to facilitate a care-friendlier environment. The study of Joubert *et al*. (2002: 20-28) has shown that, among the leading causes for care, were physical disability, frailty, urinary incontinence and stroke. About one-quarter of the care recipients in the latter study were bedridden, about one-sixth were ambulant only inside the dwelling of care, over a quarter were not able to get into or out of bed by themselves, and nearly three-quarters could never make use of transport on their own. Over half of carers spent more than 10 hours per day on caregiving activities. Large proportions of carers performed household tasks like housecleaning, doing laundry, doing dishes, preparing food; had personal care and hygiene tasks which included feeding, bathing, toileting, and dressing the care recipient; and had health care tasks such as dressing wounds and treating bedsores.

In view of the mentioned conditions and physical abilities of care recipients, and the type of caregiver activities undertaken by carers, the thesis study's findings on access to a flush toilet, hot running water, a phone, a motor vehicle, and washing machine are worrisome. Increased stresses and health risks associated with poor access to these amenities may have an impact on the health and well-being of both carer and care recipient.

6.1.4 Study results in relation to the study hypotheses

The study results, consistent with findings globally, have illustrated that women are more likely than men to be a carer, offering support for Hypothesis 1 in which it is posited that women are more likely than men to be an informal carer in the South African society.

This hypothesis contains a basic message of gender-based differences in the prevalence of caregiving in a society, but the literature shows that there are important other issues to investigate in terms of differential caregiving experiences. For example, gender differentials were found relating to time spent on caregiving; type of carer tasks; negative effect and negative consequences of caregiving; social support to carers; and levels of burden and depression.

Hypothesis 2, hypothesizing that older persons (>=60 years) and younger persons (18 - 60 years) are equally likely to be an informal carer in the South African society, was also supported by the study results. Indeed, the data showed that older persons were slightly more likely than younger persons to be a carer, but adjusting for relevant demographic characteristics of the study participants, the odds were not significantly higher in older persons. While no other quantitative South African study was found to statistically support or reject this hypothesis, there are qualitative evidence in a few empirical research studies of older persons' carer responsibilities towards other relatives or community members.

6.1.5 Shortcomings of the study

Informal care is difficult to measure, partly because it concerns goods and services produced outside the paid economy of the country, and hence is not reflected in the country's national accounts as defined by the International System of National Accounts (Department of Finance (1999), cited in Statistics South Africa, 2001). Perceptions of what constitute 'informal care' also differ among different cultures and individuals who provide such services, on top of the differences attributed to the concept by subject experts and researchers. These issues draw further attention to the shortcoming that the question was not validated prior to the survey.

A few practical issues posed additional possible weaknesses, such as the fact that the wording of the question was uncommonly long for quantitative assessment through fieldworker-administered questionnaires. Although the longer wording was chosen to facilitate comparison with other research and to improve understanding of the particular definition used, it may have been possible that some respondents found it difficult to comprehend the full meaning of what has been asked. The question appeared on the questionnaire in two of the eleven official languages of the country, which may have affected optimal understanding of the content of the question in respondents who are not fluent in those languages. The carer question was included towards the end of a particularly long and diverse questionnaire, enhancing the possibility of respondent's fatigue.

6.2 CONCLUSIONS AND RECOMMENDATIONS

In terms of numbers and proportions, it is clear hat informal carers comprise a large section of the adult population, and that the need for informal care is widespread in the country. Given the growing volume of morbidity, frailty and disability in the population, and given the mentioned constraints in formal care services, it is concluded that the estimated 7.4 million carers make an essential contribution to care provision in the country. By implication, informal carers contribute substantially to the health of the population and to savings in the health budget.

The constraints experienced in formal health care delivery seem of a longer rather than a shorter-term nature. Additionally, the shift in health service provision away from institutional settings towards community and home care implies an increased reliance on informal carers. It is therefore essential to sustain this resource. This can be done through official acknowledgement of their existence and the work they do; raising awareness among health and welfare policymakers about their essential contributions to population health; and lobbying for a comprehensive range of social, economic, health care and workplace services and supports for carers.

Lessons can be learned from the developed world where the institutional-home care shift often is compensated for by a growth in the size and range of governmental and private home care programmes, as well as the availability of programmes specifically aimed at supporting carers. Previous research in South Africa has found that carers provided a wide range of caring tasks, and that the majority were involved in physically- and mentally-draining activities—often for extended periods of time, with intensive commitments and without breaks or respite, often without the necessary skills or appropriate knowledge, and often amidst precarious financial and infrastructural circumstances. The latter study concluded that carers are an indispensable family and community asset, and recommended urgent steps in order to sustain this asset (Joubert *et al*., 2002).

Women and older persons are often referred to in government health and welfare policies as 'vulnerable members' of society. Considering women's and older persons' substantial involvement in care provision, it is important that those policies acknowledge and are sensitive to the effects of caregiving that may add to their vulnerability. Against this background, *older women* may be a particularly vulnerable segment of the South African society, calling for focussed policy and intervention initiatives.

A large part of the developed world's literature refers to differential caregiving experiences in men and women. While the majority of such studies do so to emphasise female carers' comparatively larger burden and lobby for their protection, the finding that one in four male adults in South Africa was a carer, warrants that male carers' needs, concerns and experiences also be recognised, researched and addressed.

In South Africa, limited research has been done to explore informal carers' needs, concerns and experiences, or to assess their contribution to the healthy of the population. It is recommended that a question, or rather a set of questions, be included in national, representative surveys such as the General Household Survey, to monitor informal caregiving in the country. Given the extensive prevalence of informal carers in the country, it may merit an entry in future censuses like has been done in the United States and Great Britain. Should a follow-up time-use study be conducted, it is recommended that provision is being made to allow collection and analysis of data related to informal care. This would guide formal recognition and support to such carers, and, over time, may perhaps assist in assessing the outcomes of the anti-retroviral treatment roll-out in the country.

Based on the expressed needs of informal carers in the research of Joubert *et* al., (2002), the Carers Association South Africa (CASA) was established in 2002 by Age-in-Action, the country's main non-governmental organization concerned with older persons. Through support from Age-in-Action, CASA offer information and support to carers, and assistive devices such as walking aids, bedpans, urinals and wheelchairs to care recipients. Apart from this initiative, limited official effort is being taken in South Africa to formally recognize the value of carers work, or to support them, or to campaign for their needs. It is therefore recommended that awareness be raised among relevant government departments, other non-governmental organizations, community- and faith-based organizations; social security providers; employers and the public at large about the important service delivered by such carers. Awareness rising should be followed by appropriate recognition, training and support.

Considering the widespread need for informal care in the country, and while reliance on this resource is expected to increase, a national strategy to focus on informal carers is recommended to raise awareness about their essential role and value in the health care system; to recognize their contributions to population and individual health; to comprehensively support them; and to assess and augment their needs and concerns through ongoing research in an in-depth research programme that can inform policy and facilitate evidence-based programme development.

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