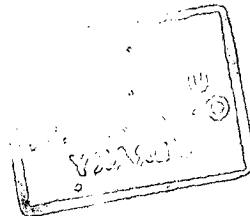Supporting those who care for the aged:
An investigation of abuse of the aged and
the relationship between carer strain and
social support networks

Derwood

D. John Hensley

Abstract

Abuse of elderly people has been widely researched over the last 20 years. A review of recent literature reveals a wide range of precursors to abuse of the elderly and an equally wide range of proposed interventions. There is wide reference in the literature however, to carer strain or the burden of care experienced by primary carers, with an emphasis on the detection and treatment of the abuser rather than on sociological factors which could lead to the alleviation of abuse or its prevention. This study investigated the place of formal and informal social support networks in relation to the level of strain perceived by primary carers of elderly persons.

A sample of 50 primary carers were asked to complete a questionnaire about the level of strain they experienced as carers and their use of and satisfaction with formal and informal support networks. The results revealed a high level of satisfaction with formal services whatever the level of perceived strain reported. A trend towards a higher level of perceived strain where the size and level of satisfaction with informal supports was lower was also shown. Implications include further examination of individual formal services and the development of strategies to enhance informal networks.

I accept this project as conforming to the required standard.

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I particularly thank the primary carers of elderly people who have taken the time from very busy and exacting daily activities to take part in the study.

Declaration

This project contains no material which has been accepted
for the award of any other degree or diploma in any
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belief it contains no material previously published, or
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D. John Hensley

November 1995

Chapter 1

Introduction

The term "Elder Abuse" is used to describe the mistreatment of older people. Abuses identified in the literature include physical, psychological and sexual mistreatment, financial exploitation and neglect. Over the last twenty years mistreatment of the elderly has been widely researched in the western world. In attempting to identify causes of abuse and ways of alleviating the problem much of the research has drawn its approach from work done in the areas of child abuse and domestic violence (Penhale, 1993). These latter social problems are predominantly approached from an individual casework or person centred perspective (Sadler, 1994), and much research in elder abuse shares this tendency.

Although elder abuse, child abuse and domestic violence have been labeled as social problems the quest for understanding and dealing with such phenomena has frequently been to consider them as "personal troubles". By tending to focus on the interpersonal aspect, such approaches concentrate the attempt to find answers to the problem in treatment of the victim and punishment of the perpetrator. Treating elder abuse merely in terms of "personal troubles" not only potentially carries the risk of blaming the victim, but also potentially

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frees the wider community from a sense of responsibility for abuse and weakens attempts to seek solutions at the societal and structural levels.

Like other forms of family and institutional abuse, abuse of the elderly predominantly takes place in private, often within the family. Regarding this behaviour simply as a social problem gives tacit recognition to the influence of existing social structures and the way in which a society provides for the needs of vulnerable groups. Such evidence of abuse is a problem for society because what occurs behind closed doors also occurs within the context of the society and thus this must be considered of community concern.

The information gained from the various person centred and casework approaches to the problem of elder abuse is important to an understanding of the issue and essential to efforts to alleviate the problem. As with other complex human problems, it is not possible or perhaps desirable to seek a single cause or a single answer. Elder abuse is a multifaceted problem and needs to be understood by considering a range of variables which have been demonstrated as critical contributors. A more comprehensive understanding may be gained by considering how interpersonal factors relate to the wider issues of formal and informal social networks as expressed in the availability of and access to specifically designed supportive services.

Provision of services to the elderly has been recognised as an appropriate and necessary response to the increase of dependency occurring with age. Statutory and voluntary organisations provide home nursing, meals on wheels, visiting the homebound, day centres, day clubs, residential and in home respite care. These are all valuable and economically justifiable services which assist dependent elderly people to remain in their own homes. Such services represent governmental and voluntary sector approaches to aged care in the community and may be viewed as the _formal_ aspect.

Aged people are often given support by family, friends and neighbours who often provide assistance with such matters as personal care, transport and shopping. In addition these people show a personal interest in the individual and may include the person who comes in for a chat or who can be called on in an emergency. This may be considered the _informal_ aspect to aged care in the community.

Thus the social network of a dependent elderly person living at home may be viewed as composed of the official structures to which they have access and the informal structures peculiar to their situation. As will be described in Chapter 2, the quality of the social network, in which many factors are outside the direct control of the individual or his or her family, exerts a significant effect on the well-being of the elderly person.

A dependent elderly person often has a primary carer who may be a spouse, child, other relative, friend or employee. The primary carer is usually a member of the elderly persons household and frequently the only other resident.

Frequently primary carers are themselves middle-aged or elderly and carry the responsibility of care day to day, night to night and week to week. Carer and cared for are part of a shared network which influences the quality of care experienced by the aged person. The demands of the role of primary carer may impair that person's ability to maintain a healthy, functional social network for themselves and limit their ability to assist the elderly person maintain his or her own network. Moreover, the social networks of the elderly in general are eroded by changes associated with age, such as diminishing physical energy, increasing frailty, lessening mobility and loss of friends and relatives through death and illness. Thus the main burden of maintaining networks for the dependent elderly often falls increasingly on the primary carer. Consequently, a primary carer's well-being may be impaired by the difficulty of maintaining their own social network and that of the cared for person.

Only the totally self-sufficient few can exist without some form of social network. The quality of the formal and informal social network determines whether or not an individual will experience it as supportive, giving a sense of being respected

and valued, or as de-humanising, impersonal, uncaring, even
degrading. The formal network needs to be designed to deliver
services which support healthy, functioning, appropriate
informal networks and facilitate their maintenance. Anecdotal
evidence gained in the writer's professional practice suggests
that some currently available formal networks can be perceived
by carers as imposed forms of help that do not fully meet
needs and which will be withdrawn if the recipient displays
non-conformity to the pre-determined design. Some criticism
has been leveled at the way in which some services are
delivered, for example, services which are designed to fit the
schedule of the service provider rather than the needs of the
recipient. Where service providers, such as home help and home
nursing services control the form and delivery of a service,
the people served become passive recipients rather than
partners in the giving and receiving of help. Offered formal
services may be refused because they are not flexible enough
to meet needs and where people are unable to negotiate the
type of help they need and can use. This may lead to services
being rejected by the elderly and their carers while important
needs remain unmet and possibly unrecognised.

When formal services are rejected or inappropriately used and
when informal networks are unsatisfactory there is likely to
be a higher level of strain on the primary carer. This may
influence the possibility of elder abuse. Therefore
identification of those aspects of social support networks

which are likely to produce higher levels of carer strain may provide a basis from which strateges to combat elder abuse may be developed.

The purpose of this study is to explore the relationship between the level of strain experienced by primary carers of elderly persons and their use of and satisfaction with their total support networks. The results from this study will indicate which aspects of informal social networks are critical to the alleviation of carer strain. Results will also enable providers of formal services to recognise whether areas of service provision and delivery need to be more "user friendly". The study will therefore have significance to service providers through its focus on issues within informal and formal support networks that exacerbate or alleviate strain for primary carers. In this way the results may contribute to an enhanced understanding of elder abuse and thus suggest measures which may be useful in preventing or reducing its occurrence.

Chapter 2

Review of the Literature

2.1 Elder Abuse

2.1.1. Frequent approaches to the study of elder abuse.

Although abuse of the elderly can take place in all living situations abuse is usually studied in relation to abuse from or towards the elderly person's primary carer or others closely involved in their care (O'Brien, 1994). One definition of elder abuse that has remained useful is *"systematic and continuous abuse of an elderly person by the carer, often but not always a relative on whom the elderly person is* dependent *for care"* (Cloke, 1983 p. 2). In Australia this perception remains current. Kurrle (1994) states that 80% to 90% of abusers are close family members who live with the victim, indicating that the abuser is likely in most cases to be either the carer or cared for person.

The recent trend in the literature is to focus on the psychological issues surrounding the relationship between the carer and cared for person as well as the incidence of any psychopathology or entrenched behavioural abnormalities (Bennett, & Kingston, 1993, Kurrle, 1994, Sadler, 1994).

Consequently this has led to a "seek out and treat" approach to the problem at the level of the individual victim and abuser. Profiles of the typical victim have been drawn as have psychosocial and psychopathological profiles of potential abusers. In conjunction with this research elder protection protocols have been produced and are based on dealing with the issue as primarily a personal problem of the elderly and their families (Moran, 1993, Pritchard, 1992).

This approach has frequently been based on child abuse and domestic violence models and has resulted in a wide range of suggested legal approaches to the issue. Mandatory reporting, as is the case in much of the United States of America, the development of "at risk" registers in parts of Australia (Sadler, 1994, N.S.W. Task Force 1993) and the use of guardianship (Coker, 1994, Thomas, 1994) are all examples of the development in this field.

2.1.2. Seeking risk factors.

Determining possible causes of elder abuse is a complex matter. Different types of abuse have been shown to have different causes (McCreadie, 1993) and large a number of factors which may indicate the possibility of abuse have been suggested. These factors can be placed into three clusters:-

a). Personal issues, b). Relationship issues, c). Socio-economic issues.

The critical personal issues seem to be the increasing physical and mental dependency of the person being cared for (Bennett, 1993, Kingsley, 1993, Pritchard, 1992) and to the stress, burden, personality, psychological and psychiatric status of the carer. There is a clear indication of a positive relationship between increased dependency and carer stress and burden.

Relationship issues include histories of family abuse, disruptive behaviour, conflict, poor relationships and poor communications (Kurrle, 1994). Role reversal and the changed nature of an established relationship are seen as influencing factors. Social isolation is also a factor in this cluster.

Socio-economic issues include financial problems resulting from such things as carers having to give up paid work and additional costs involved in providing care. Inadequate, poor and overcrowded accommodation are seen as indicators of possible abuse within the socio-economic area (Bennett, 1993, Kingsley, 1993, Pritchard, 1992, Vida, 1994).

All these factors can add to the burden of caring experienced by primary carers. Different people react in different ways,

have different tolerance levels to the burden of caring and experience different intervening variables which influence their coping ability (Nolan, 1993). Therefore, when considering the effect of the burden of caring and the strain it imposes on the individual, it is necessary to examine the carer's perception of the particular situation. The inability of individual carers to deal with the dependency of those they have to care for has been frequently cited as the reason for mistreatment in the home (Frost, 1994).

It is made very clear (Vida, 1994) that when looking at the above risk factors great care must be taken not to see them as the causes of abuse. They should be recognised as correlates of abuse or neglect, doing no more than showing that there is a degree of relationship between abuse and these variables. (Vida, 1994).

2.1.3. Dealing with abuse.

As the factors that result in abuse are complex and varied, attempts to deal with the issues have used a range of different interventions. Intervention comes after a problem has been identified and classified by an assessor or a service provider and is put in place to alleviate the consequences of an abusive or potentially abusive situation. The type of

intervention will depend on the nature of the abuse or
potential abuse. Some suggestions are:-

- that physical abuse may require the immediate removal of the
  victim
- respite care may be used to alleviate stress
- treatment of the abuser is recommended where psychopathology
  is identified
- family counselling may be used to enhance coping skills
- legal intervention where there is financial abuse (Kurrle,
  1993).

Such approaches appear to be a consequence of focusing on the
primary carer and cared for person and dealing with the
question of abuse as a "private trouble".

2.2. Social Networks.

The type of social network to which an elderly person belongs
has a significant bearing on the level of care and protection
experienced. A typology of social networks for use by
community care workers has been developed by Wenger (1994).
Wenger's typology is based on a longitudinal study carried out
between 1979 and 1991. Pilot studies of the usefulness of the
typology in practice were conducted by six health care and
social services teams in England and Wales during 1990 and
1991. This typology reflects the type of relationship which
elderly people have to their network. The five types are:-

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Local Family Dependent. These networks are based mainly on the

local family and include spouse and children. Little or no

practical assistance is expected from or given by friends and

neighbours. Although it usually provides adequate support in a

minority of cases malfunction leads to poor care, neglect and

abuse. It is very much a closed system.

Locally Integrated. This type of network not only involves the

immediate family but includes friends and neighbours. There is

usually a wide range of help available and a high level of

autonomy is maintained. Elderly people in such networks often

recognise the level of burden on the network and use

appropriate community services to reduce the level of strain.

It appears that locally integrated networks lend themselves to

collaboration within themselves and between themselves and

formal services.

Local Self-Contained. Members of this network type often have

nobody outside the household (sometimes the primary carer

alone) to provide practical or emotional assistance in the

long term. There is often a high level of dependence on formal

services and early admission to residential care.

Wider Community Focused. This network type involves people who

have family and interests outside the local community. They

have often migrated to new locations on retirement. People in

these networks are likely to be their own case managers and
arrange paid support. Difficulties arise when mobility is
restricted and higher level care is required.

Private Restricted. Typically a very small network, perhaps
only husband and wife or two close friends. Higher levels of
dependence and the loss of partner lead to early need of
residential care.

It is clear from Wenger's research that as the individual ages
and becomes more dependent and in need of higher level care
all the networks experience significant pressure. She proposes
that the one most likely to be able to adapt in the face of
pressure is the *Locally Integrated Support Network* because of
its size, heterogenaity of composition and ability to use
formal services (Wenger, 1994).

In Israel attempts have been made to develop this type of
network. A program aimed at reducing individual strain and
enhancing coping ability has been set up to teach families to
develop the ability to share common concerns with other local
families and to involve formal service providers (Csillag,
1989).

Changes in the size and the intensity of help occur when there
is increasing frailty and deteriorating health and reduced
functional ability in the older person (Stoller, 1983) and not

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in response to the burden experienced by the primary carer (Miller, 1991).

It is suggested by Twigg, Atkin and Perring,(1991) that an often neglected but central part of the usefulness of formal and informal intervention is whether or not carers' needs and their level of strain is taken into account by members of informal networks and formal service providers. Consideration of the level of satisfaction that primary carers have with help from others in their informal care network and from formal services is also seen as necessary (Parker, 1992). Availability of appropriate and satisfying social support that takes account of the carer's personal and social needs is seen to be related to higher levels of well-being and life satisfaction generally and to the ability to cope with caring duties (Moryez, 1985, Mui, 1992, Wilson, 1990).

The state of the carer's own health clearly has a bearing on their ability to cope. It is suggested that supportive interpersonal relationships may have an influence on this (Kiecolt-Glasser, & Glasser, 1990). It is not so much the actual burden on caregivers that influences coping ability as their perception of burden. Where the carer is able to recognise and accept the value of the support of others the feelings of burden are reduced. It is thus seen as critical in caring for the elderly in the community that the carer is not left without appropriate support (Zarit, 1980).

2.3. Support networks and elder abuse.

Without losing sight of the personal and psychological issues involved in the abuse of the elderly consideration should be given to the carer and cared for person in their social context. Such an approach recognises the carer's position within the overall informal and formal support systems (Twigg, Atkin, and Perring, 1991). It also enables highlighting of the strengths and weaknesses of the way in which the formal and informal networks interact with each other (Barer, 1990) and with the primary carer.

2.3.1. Better social networks: less abuse?.

In many situations where elder abuse has been reported and various psychopathologies and sociopathologies of the abuser have been isolated a secondary factor of poor social networks has frequently been present (Wenger, 1994). Three thousand people over sixty five were surveyed in 1985 and 1986. Results indicated that along with other factors there was an association between the mistreatment of elderly people and the existence of poor social networks (Lachs, 1994). It was noted by Lachs *et al* (1994), however, that poor social networks were more strongly associated with elder abuse in non-minority groups.

2.3.2. Filling the gaps or total care?

Informal networks play a significant role in the care and support of the elderly. Garbarino (1986) has been cited as suggesting that the evidence points to good networks helping to reduce depression and domestic violence (Coulshed, 1988). She also cites the work of Gottlieb (1981) as showing the enhancement of mental health through the existence of strong and active social networks.

A certain amount of work was carried out in the United Kingdom in the 1980s. This aimed to create partnerships between formal services and informal social networks for provision of care and support to various groups of people in the community. Demonstration projects were set up with small locally based teams working with the natural networks in the local area. Although these programmes were not without their critics there is evidence that they were effective in establishing more co-operative working relationships between professionals and informal community networks (Coulshed, 1988).

It is not clear whether these projects actually complemented the informal care or supplemented it. What is clear, however, is that the majority of formal services do not complement the informal care in place but are merely a supplement to it. Indeed, often when an informal source of care exists formal services may not be offered (Challis, & Davies, 1985). Where

there is a primary carer the likelihood of formal services

being offered is significantly reduced:-

Confused old people who lived alone and were supported by
relatives nearby were nearly twice as likely as those living
in the same household as there supporting relatives to have
been provided with home help (Twigg, Atkin, & Perring, 1991 p
30)

Thus there is a failure to recognise the needs of primary

carers.

2.3.3. An integrated approach.

It has been long recognised that a multi-disciplinary approach

to the provision of formal services to the aged population is

necessary (Decalmer, & Glendenning, 1993, Kingsley, 1992,

Kingston, 1994, O'Brien 1994). Such an approach is likely to

increase the primary carer's knowledge and understanding of

availability and accessibility of existing services and lead

to appropriate service use (O'Brien, 1994). The concept of a

multi-disciplinary approach implies a coordinated approach. In

practice this often is not the case. It must therefore be

underlined that service coordination is vital (Jones, 1994). A

coordinated, multi-disciplinary approach, able to accept

professional services, family and the informal network is

required.

Within families the burden of care may fall on one person causing considerable sacrifice. This burden can be reduced where other family members, friends and neighbours are able to work with the primary carer. The importance of these secondary informal networks needs to be recognised and utilised. They need to be recognised by the primary carer and they also need to be recognised by the formal service providers. There is a need for a relationship to be established between formal and secondary, informal networks that enables them to work co-operatively in the provision of care and support (Cantor, 1985). Formal networks need to develop an understanding of the role of the informal networks and negotiate partnerships and to bridge the gap between formal and informal care (Sharkey, 1990, Timms, 1983).

2.4. Summary.

Studies of elder abuse have tended to focus on the characteristics of the carer and the cared for, and the relationship between them. While these factors are important, they can result in attention being unduly concentrated on detection and treatment after abuse has occurred. Less consideration is thus being given to the primary level prevention.

The type and level of functioning of the social network shared by carer and cared for will affect not only the amount and quality of support available but also the carer's perception of the demands of the caring situation. Appropriate, supportive, formal and informal social networks have been shown to significantly increase a carer's ability to cope with the tasks involved in providing care. Poor social networks have been found to correlate with elder abuse in some studies. Formal services for the elderly and informal sources of help are often poorly integrated. It is argued that appropriate and effective services able to minimise the risk of abuse need to be integrated, multi-disciplinary and co-ordinated. Formal and informal networks need to recognise each other's value and work in partnership to ensure the risks of abuse are minimised.

2.5. Goals of the Study

In Tasmania, research has not been directed to investigatyion of the relationship between abuse, carer strain and the possible impact of the availability and quality of formal and informal social support networks. As the review above has indicated, there is evidence to suggest that carer strain is a significant factor in elder abuse and that such strain is reduced where informal supports are appropriately integrated with formal services. The present study focuses on percieved carer stress in relation to support networks and formal

services as experienced by a group of primary carers of frail elderly persons in southern Tasmania.

The literature makes it clear that no single cause of elder abuse can be isolated and thus there is no single method of dealing with the problem. It is, nevertheless, strongly indicated that certain common factors occur in a wide range of situations in which abuse occurs or has the potential to occur. The level of strain perceived by carers is a recurring issue and so is the degree of satisfaction that carers have with the informal networks and formal services.

This study seeks to determine whether a relationship exists between the level of strain experienced by carers in southern Tasmania and their satisfaction with available informal and formal support networks. Should the results of the study indicate a strong relationship then an appropriate approach to the prevention of elder abuse would lie in the development and promotion of co-ordinated, interactive and complementary formal and informal support networks.

Chapter 3

Method

3.1. Subjects.

The subjects for this study were 46 primary carers living in southern Tasmania in the cities of Hobart, Glenorchy and Clarence and the municipalities of Kingborough, Huon and Spring Bay. These were carers of people referred to the Southern Region Assessment Team for assessment and assessed as eligible for either nursing home respite or permanent nursing home care. For the purpose of this study a primary carer was defined as an individual living with the person for whom they were caring.

A systematic sample of 50 carers was identified. First a list was made of clients assessed between 1/6/94 and 1/6/95 as eligible for permanent or respite care in a nursing home and who were living with a carer. Starting at 1/6/95 and working in reverse order every third client was selected until 50 clients had been selected.

The systematic sampling method was used to ensure subjects met the criterion of being primary carers of dependent aged

persons (Gay, 1992). The list from which the sample was taken
does not include all primary carers but only those who have
been assessed and classified as indicated above by the
Southern Region Assessment Team.

3.2. Instruments.

To determine the correlation between carer strain and the use
of and satisfaction with informal and formal support networks
50 primary carers were surveyed using two standardised
questionnaires and one purpose developed questionnaire.

The questionnaires were administered as a single questionnaire
comprising: *Part A: Caregiver Strain Index, Part B: OARS
Social Resource Scale* and *Part C: Formal Support Services
Questionnaire.*

3.2.1 The _Caregiver Strain Index_ (Butler,Fricke & Humphries.
1993.) (Appendix A) is a thirteen item questionnaire requiring
"yes" or "no" answers to each item. The estimated time for
completion was approximately five minutes. It is
comprehensive and covers a wide range of factors that both
anecdotal and literature based evidence suggest as indicators
of strain. The index seeks information about physical,
emotional and social issues that can be experienced by a
carer. The index has been used with a wide age range,

including the elderly and middle aged and also with carers

providing different levels of care. Regarding the reliability

and validity of the index, reviewers report:-

*Scores on the CSI have been found to be significantly
correlated to the characteristics of the person being cared
for, particularly their ability to perform ADLs and their
cognitive status; to the caregivers overall perception of the
situation; and to the caregivers emotional status. These
results indicate that the Index has achieved a certain level
of validity. The items in the CSI are also highly related to
one another, which is a good indicator of reliability* (Butler,
Fricke & Humphries. pp. 48 -51 1993).

The Index was deemed suitable for the purpose of this study as

it is not overly intrusive, is brief and has appropriate level

of language usage. It has been used successfully with a wide

age range and with persons caring for individuals with a

variety of impairments, including Altzheimer's disease.

3.2.2 *The OARS Social Resource Scale* (Butler, Fricke & ·

Humphries)(Appendix B) is designed to measure social and

family contact amongst older people. Reviewers of the

instrument report:-

*It is targeted to older people and can be used both with older
people living in the community and those in residential
care.....It can be used as a screen to identify clients who are
socially isolated....The OARS social resource scale is brief,
easy to administer, of obvious and immediate relevance to both
assessors and clients and is valid and reliable* (Butler,
Fricke and Humphries. pp.37 - 42).

This instrument seeks information about the size of the

respondents circle of family and friends. It seeks information

about the frequency of telephone and face to face contact with

people outside the respondents own household, covering the

scope and quantity of interaction experienced by the respondent. It also seeks information about the way that the respondent feels about the amount of contact. Thus the respondent's perception of the quality of contact is canvassed.

Studies such as Brown et al.,1990; Zarit et al., 1986, have shown the OARS scale to be an important predictor of the increased use of community services by carers.

3.2.3.*The Formal Services Questionnaire* (Appendix C) was designed by the researcher to determine clients' knowledge of, use of and satisfaction with formal community support services. The questionnaire has three sections. The first section asks respondents about their knowledge of specific services. A list of seven widely used services is given and respondents are asked to indicate which ones they know about. The second section asks what services they use. A list of the same seven services is given and respondents are asked to identify those that they have used or are using. An eighth space is given for any other services that the respondent may use. The third part makes ten statements and asks respondents to indicate on a five point Likert scale whether they agree with each statement. These statements seek the respondents satisfaction with the services they use.

3.3. Administration of the instruments.

Application was made to the University of Tasmania Ethics Committee (Human Experimentation) and approval received to carry out this study and to administer the instruments in the way described.(Appendix D) Application was made to the Team Leader of the Aged Care Assessment Team in Southern Tasmania to administer the instruments in the way described (Appendix E). Approval was received (Appendix F) During the first and second weeks of August 1995 a systematic sample of 50 primary carers was identified from the records of the Aged Care Assessment Team in Southern Tasmania. Between the 14th. of August and 23rd of August 1995 each person was telephoned and asked if they would take part in the study. A standardised approach was used with each subject (Appendix G). Copies of the questionnaire were then mailed to the members of the sample who had agreed to take part. A copy of the procedure to be used to ensure confidentiality (Appendix H), a note of thanks for taking part and giving a date for return of questionnaires (Appendix I) and a numbered stamped addressed envelope were enclosed.

When the returned questionnaires were returned the number on each envelope was checked against the corresponding number on the list of subjects. On the 4th of September the list of subjects was destroyed and the questionnaires were opened.

The procedure outlined Appendix H was carried out.

3.4. Data Analysis.

The individual scores recorded by the *Carer Strain Index* were
ranked from highest individual score to lowest individual
score. The scores of seven and above were rated as "High Level
of Carer Strain" and the scores below seven as "Low Level of
Carer Strain". The total scores for each question in the *Carer
Strain Index* for each of the two groups were compared to see
what variation there was in the way the groups responded.

The total scores for each question in the *OARS Social
Resource Scale* and the *Formal Services Questionnaire* for the
"High Level of Carer Strain" group and the "Low Level of Carer
Strain" group were compared to determine the variation between
the two groups in their response to each question.

The scores as recorded by the *Carer Strain Index* were
correlated with the corresponding scores on the *Social
Resources Scale* and the *Formal Support Services Questionnaire*.
This provided two separate coefficients of correlation. These
were compared to see if a significant difference existed
between them.

To explore whether certain key issues had potential influence on the level of carer strain the two following correlations were carried out:

(1) The scores on the *Carer Strain Index* were correlated with the corresponding scores from the questions related to satisfaction in the *OARS Social Resource Scale.*

(2) The scores on the *Carer Strain Index* were correlated with the corresponding scores from the questions related to the availability of help in times of sickness or disability in the *OARS Social Resource Scale.*The correlations were carried out using a Casio *fx*-180P scientific calculator.

Chapter 4

Results

4.1. Responses to Questionnaire.

The initial telephone contact with 50 individuals was well
received and all expressed pleasure at being asked to assist.
A few questioned their ability to complete the questionnaire
but said they would be willing to try. Some reported that they
were no longer primary carers because the person they had
cared for had either died or entered residential care; they
were, nevertheless, prepared to answer the questionnaire. All
fifty people contacted agreed to have a copy of the
questionnaire sent to them.

Forty-six (92%) questionnaires were returned. Not all
respondents had completed all questions in all parts of the
questionnaire. One respondent left Part A blank with a note
that the questions did not apply to her, one respondent
completed only two questions and one completed 12 of the
thirteen questions. All other respondents completed all
questions in Part A. Two respondents did not complete any
questions in Part B, one completed only two questions, thirty
seven completed all questions in the part and the remaining
six did not complete between one and four questions.

All questions in Part C were completed by thirty five respondents, six respondents answered no questions in the part and one question was not answered by each of the remaining four. In total 91% of the questions were answered.

Unanswered questions in Part A, *The Carer Strain Index*, were rated as being a negative response and were counted as zero. Unanswered questions in Part B, *Social Resource Scale*, were given a rating of zero. In the *Formal Services Questionnaire* or Part C, unanswered questions were included with those who answered that they were undecided. Where individual respondents have not answered any of the questions in one part of the questionnaire their responses have been omitted from correlation computations that include that particular part of the questionnaire.

4.2 Carer strain index.

It is suggested by Robinson (1983) that a positive response to seven or more questions in the *Carer Strain Index* indicates a "greater level of Stress". In this study 26 (or 56.5% of) respondents scored 7 or more and 20 (or 43.5%) including one who reported that the questions did not apply to her, scored less than 7. The individual scores ranged from a high of 12 out of a possible 13 positive answers to a low of zero. The distribution of the scores is shown in Table 1.

Table 1

Distribution of Individual Scores of

Respondents on the *Carer Strain Index*

SCORE	NUMBER OF RESPONDENTS	
12	4	
11	2	High
10	6	Strain
9	9	Group
8	1	
7	4	
6	2	
5	8	Low
4	3	Strain
3	1	Group
2	4	
0	2	

An analysis of the individual questions in this section shows
a significantly higher positive response by the high strain
group to all questions. The difference between the two groups
varies from question to question. Table 2 shows the variation
between the High Strain Group and the Low Strain Group in
response to the each question in the index.

(NOTE: In the Following Tables the heading High represents the
High Level of Strain Group and Low represents the Low Level of
Strain Group determined from scores in the *Carer Strain Index*.
There are 26 respondents in the High Level of Strain Group and
20 respondents in the Low Level of strain group. (N) following
High and Low denotes the number of respondents shown below
it).

Table 2

Variation Between the High and Low Strain Groups in

Responses to Each Question in the *Carer Strain Index*.

Questions	High (N)	Low (N)
1 Sleep is disturbed	81%(21)	45%(9)
2 It is inconvenient	85%(22)	25%(5)
3 It is a physical strain	92%(24)	35%(7)
4 It is confining	100%(26)	65%(13)
5 There have been family adjustments	73%(19)	25%(5)
6 Personal plans have been changed	96%(25)	60%(12)
7 Other demands on time	38%(10)	10%(2)
8 Emotional Adjustments	77%(20)	25%(5)
9 Some behaviour is upsetting	92%(24)	25%(5)
10 Upset by changes in one cared for	85%(22)	20%(4)
11 Work adjustments	19%(5)	0%(0)
12 Financial strain	27%(7)	5%(1)
13 Feeling completely overwhelmed	85%(22)	35%(7)

The mean percentage difference between the group showing a

high level of strain and the group showing a low level of

strain is 44%. Questions 9 (upsetting behaviour) and 10

(changes in the cared for person) show a difference

considerably higher than the mean (44%), 67% and 65%

respectively. There is also a difference (60%) considerably

higher than the mean (44%) in question 2 (inconvenience).

There is a lower difference (35%) than the mean for question 4

(confining), for which each group shows its highest score,

100% for the high level of strain group and 65% for the low

level of strain group. The high level of strain group shows a

high score in both questions 2 and 4, which could be

expected as the both questions place similar constraints on

carers. The low strain group, however, shows a low score in question 2 but its highest in question 4 which is surprising as it would be reasonable to expect being confined and inconvenience to be strongly related.

The low score from both groups in question 11 (work adjustments) may be related to the age group of the respondents. The age of respondents was not asked for but as one respondent volunteered "It should be noted that this is an 80 year old caring for an 82 year old". Because of the nature of the sample it is likely that such a note would apply to many of the respondents.

It might be expected that question 12 (financial strain) would have had a higher positive response than it did. Only 5% of the low strain group and 25% of the high strain group said they experienced financial strain.

The variation in the responses by the two groups to each of the thirteen questions in Part A of the questionnaire are illustrated by the following Hi-Lo chart (Figure 1). Figure 1 is a graphic illustration of the percentages shown in Table 2, clarifies the overall response pattern and shows the variation in responses between the two groups to each question. Figure 1 also illustrates that work adjustments and financial strain were not major issues for either group.
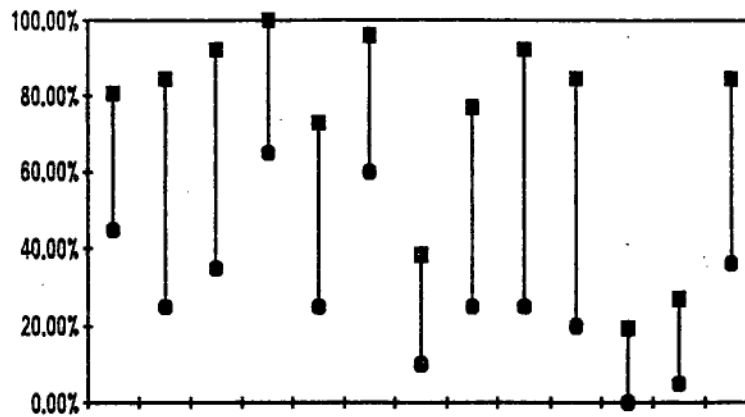
Figure 1. Chart of responses to individual questions in *Carer Strain Index* by high level and low level of strain groups.

Square symbol = High group. Round symbol = Low group.
Lateral axis shows from left to right questions 1 to 13.
Vertical axis shows percentages of positive answers to each question.

4.3. Social resource scale.

In this section and the following section, "Formal Services", the data gathered from the higher level of strain group in the *Carer Strain Index* will be presented separately from the data from the Lower Level of Strain Group. Thus comparison can be made between the two groups in relation to their responses to part B and part C of the questionnaire enabling the degree of relationship between the level of carer strain and social networks and services to be determined.

The first question in this part dealt with the type of household in which the respondent was living. Table 3 shows these.

Table 3

Type of Household in which Carers' are Living.

Carer Living With *	**High (N)	***Low (N)
A. No one	12% (3)	25% (5)
B. Husband or wife	81%(21)	45% (9)
C. Children	8% (2)	5% (1)
D. Grandchildren	0% (0)	5% (1)
E. Parents or Parent	12% (3)	15% (3)
F. Grandparent/s	4% (1)	0% (0)
G. Brothers and/or sisters	4% (1)	10% (2)
H. Other relatives	0% (0)	0% (0)
I. Unrelated person/persons	0% (0)	0% (0)
J. Other (specify)	0% (0)	0% (0)

*The total responses are more than 100% (46) because 5 respondents answered in more than one category. One answered BC, one BE, one BG, one BCE and one BDCE.
** High = High Level of Strain Group.
*** Low = Low level of Strain Group.

Eight respondents stated they were living alone. This is accounted for by the fact that the person for whom they had been caring had either died or entered long term residential care during the previous twelve months. Thus, although, all respondents had been carers during the past twelve months eight had ceased that role at some stage during that time.

It is noted that in the high level strain group 81% (21) of the respondents were living with their spouse whilst of the low level of strain group there were only 45% (9) in this situation. Of the carers living with their spouse and others 15% (4) were from the first group and 5% (1) from the second

group. Thus 65% (17) of the high level strain group lived with their spouse only compared with 40% (8) of the other group.

The two groups answered the remaining questions in the *Social Resource Scale* as follows:-

Table 4

How many people do you know well enough to visit in their own homes?

*People Known	**High (N)	***Low (N)
Five or More	35% (9)	50% (10)
Three to four	35% (9)	15% (3)
One or two	23% (6)	5% (1)
None	4% (1)	15% (3)
No Answer	4% (1)	15% (3)

* People Known = People known well enough to visit in their own homes.
** High = High Level of Strain Group.
***Low = Low Level of Strain Group.

The high strain group shows a higher score in the number of people it knows well enough to visit than the low strain group. A total of 93% (24) of the high strain group reports knowing at least one person well enough to visit compared with 70% (14) in the low strain group.

Table 5

How many times did you talk to someone - friends,
relatives, others - on the telephone in the past
week (either you called them or they called you)?

Number of Times	High (N)	Low (N)
Once a day or more	27% (7)	25% (5)
Two to six times	50% (13)	60% (12)
Once	8% (2)	0% (0)
Not at all	11% (3)	0% (0)
No answer	4% (1)	15% (3)

There is little difference between the two groups in the
number of telephone calls made, of the high strain group 85%
(22) report at least one telephone contact the same percentage
as the low strain group. In the low strain group, however, the
85% (17) report multiple telephone contacts. In the high
strain group 11% (3) report having no telephone contact.

Table 6

How many times in the last week did you spend some
time with someone who does not live with you; that
is, you went to see them, or they came to visit you
or you went out to do things together?

Number of Times	High (N)	Low (N)
Once a day or more	15% (4)	10% (2)
Two to six times	19% (5)	40% (8)
Once	35% (9)	15% (3)
Not at all	31% (8)	20% (4)
No answer	0% (0)	15% (3)

50% (10) of the low level strain group report multiple face to
face contacts compared with 34% (9) of the high strain group.

36

Overall the high strain group reports slightly less face to face contact than the low strain group.

Table 7

Do you have someone you can confide in?

A Confidant?	High (N)	Low (N)
Yes	85% (22)	85% (17)
No	15% (4)	0% (0)
No answer	0% (0)	15% (3)

Clearly there is little difference between the two groups. It would have been interesting to have asked the question in a different way to see if the trusted confidant was the person being cared for or another.

Table 8

Do you find yourself feeling quite lonely?

How Often Lonely?	High (N)	Low (N)
Quite often	27% (7)	10% (2)
Sometimes	58% (15)	35% (7)
Almost never	15% (4)	40% (8)
No answer	0% (0)	15% (3)

The percentage of the high strain group who often or sometimes experience loneliness is higher than those in the Low group. In the high strain group 85% (22) report more than very occasional loneliness compared with 45% (9) in the low strain group.
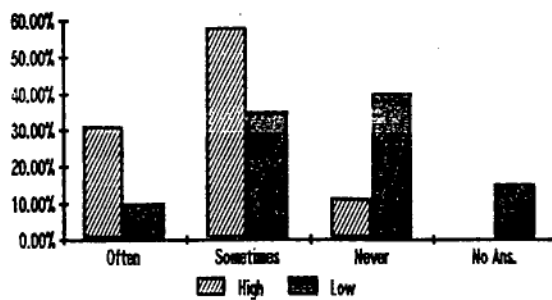
<u>Figure 2</u>. Chart of group responses to loneliness

Table 9

<u>Do you see your friends and relatives as often as
you want to, or are you somewhat unhappy about how
little you see of them?</u>

Contact Satisfaction	High (N)	Low (N)
As often as I want to	23% (6)	55% (11)
Somewhat unhappy	73% (19)	30% (6)
No answer	4% (1)	15% (3)

The low strain group express greater satisfaction with their
contact with others than the high strain group.
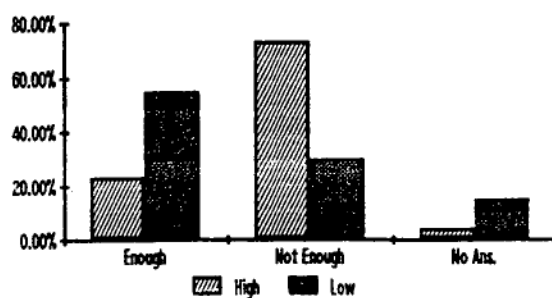
<u>Figure 3</u>. Chart of satisfaction with contact of groups

There is little difference between the two groups in their
responses to the questions that ask about the number of people
they know and the number of contacts that they have each week.
There is, however, a marked difference in the level of
satisfaction shown with the Low level of strain group showing
significantly higher satisfaction.

Therefore in this section of Part B of the questionnaire it
can be seen that there is little difference in the social
resources available to each group but the satisfaction of the
High level of strain group is considerably less than that of
the Low level of strain group.

The following two questions are treated separately in the *OARS
Social Resource Scale's* rating scale. The availability of
help in time of sickness or disability and the length of time
that help is available for are seen as significant indicators
of social well-being or impairment.

Table 10

Is there someone who would give you any help at all
if you were sick or disabled?

Assistance Available	High (N)	Low (N)
Yes	69% (18)	60% (12)
No-one willing AND able....	27% (7)	20% (4)
No answer	5% (1)	20% (4)

Table 11

Is there someone who would take care of you..

Will care for	High (N)	Low (N)
...as long as needed?	*39% *(7)	*45% *(5)
...few weeks to six months?	* 0% *(0)	* 0% *(0)
...now and again?	*61%*(11)	*36% *(4)
No answer	* 0% *(0)	*18% *(2)

* = % and Numbers of respondents who had someone who was willing and able to provide help.

The High level of strain group showed 69% (18) with somebody willing and able to help in times of sickness or disability but of that figure 61% (11) would only be able to provide help now and again. The examples given for help "now and again" were "take you to the doctor" or "fix lunch" in other words minimal help. There were 27% (7) in the high level of strain group who said they would have nobody willing and able to help. So in this group a total of 69% (18) had minimal or no help available.

In the low level of strain group 55% (11) indicated the availability of help and of that number 45% (5) indicated help for as long as needed and 36% (4) indicated minimal help. In this group no help or minimal help would be available to 40% (8). In this group 25% (5) did not answer the question on availability of help and of those who said that help would be available to them 18% (2) did not respond to the question of how much help would be available to them. Thus 35% (7) of the

total 20 respondents in the low level of strain group did respond to these two questions compared with 5% (1) in the high level of strain group.

The final question in this part of the questionnaire asked who would be available to give care in case of sickness. The majority in both groups said a relative.

4.4. Formal services.

The first question in this part seeks to understand respondents' knowledge of services that may be available to them. As the persons being cared for by all the respondents have been assessed by the Aged Care Assessment Team they should all have been given information about available services at some stage during the assessment process. It is therefore expected that there would be a good knowledge of the existence of the services listed. This is only partially borne out by the responses received. The group with the lower level of carer strain overall indicated a lesser knowledge of services than the group with the higher level of carer strain.

Table 11 shows the number of respondents who were aware of particular services.

Table 12

Services known by Respondents

Services	High (N)	Low (N)
A. Community Nursing	85% (22)	80% (16)
B. Home Help	58% (15)	60% (12)
C. Handyperson service	31% (8)	15% (3)
D. Meals on wheels	88% (23)	55% (11)
E. In-home respite	50% (13)	25% (5)
F. Residential respite	65% (17)	45% (9)
G. Community Transport	42% (11)	30% (6)

Table 12 shows the number of respondents from the high level of strain group and the low level of strain group using particular services.

Table 13

Services used by Respondents.

Services Used	High (N)	Low (N)
A. Community Nursing	69% (18)	70% (14)
B. Home Help	27% (7)	40% (8)
C. Handyperson Service	4% (1)	5% (1)
D. Meals on Wheels	19% (5)	30% (6)
E. In-home respite	27% (7)	5% (1)
F. Residential Respite	54% (14)	30% (6)
G. Community Transport	19% (5)	20% (4)
H. Other (specify)	4% (1)	0% (0)

Both the high level of strain group and the low level of

strain group show an equally high level of use of community

nursing services. The high level of strain group uses less

home help than the low level of strain group but this can be

offset by its higher use of in-home respite. The high level of

strain group uses considerably more residential respite than

the low level strain group. The handyperson service is used by

very few in each group. Only one respondent indicated the use

of any service other than those listed, this respondent was

from the high level of strain group and that person specified

Family Based Care.

The overall use of services by the high level of strain group

and the low level of strain group is similar, however there is

some variation is the types of services used by each. This

chart shows how the use of the services is distributed.
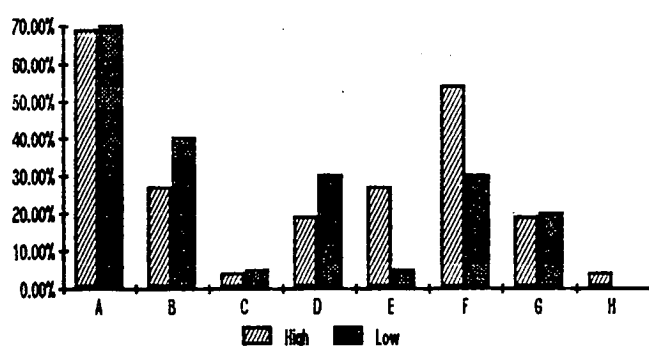
Figure 4. Chart of use of services by groups

The remaining questions in this part seek to find out whether

or not respondents are satisfied with the services. The

questionnaire used a five point Likert scale asking whether
the respondent strongly agree, agree, are undecided. disagree
or strongly disagree with each of ten statements.

In the analysis of the responses an answer of strongly agree
or agree is considered to indicate satisfaction with services.
Where the answer is that the respondent strongly disagrees or
disagrees it is considered to indicate dis-satisfaction with
the services. Where respondents did not answer a question they
have been grouped with those who have indicated that they are
undecided about that particular issue.

Of the group that showed a high level of carer strain 67%
indicated a general satisfaction with the services they used,
9% indicated dis-satisfaction and 23% were undecided. The low
level of carer stress group indicated 49% were satisfied with
services, 36% were undecided and 15% were dis-satisfied. The
statements with which they were asked to state their agreement
or disagreement were:-

        A. I would recommend the services I use to other carers.
        B. The services I use meet my needs.
        C. The services I use fit in with my schedule.
        D. Service providers take my wishes into account.
        E. I have input into what services are provided.
        F. I am able to negotiate changes in services.
        G. I have a good working relationship with service
        providers.
        H. I am able to make suggestions about services.
        I. The services help to reduce my workload.
        J. I would have difficulty managing without services.

The following table (Table 13) shows the way in which the two
groups responded to the above statements.

Table 14

Level of Satisfaction with Formal Services.

	* Satisfied		Dis-satisfied		Undecided	
	High	Low	High	Low	High	Low
A.	85%	55%	8%	15%	8%	30%
B.	58%	55%	12%	10%	31%	35%
C.	73%	40%	4%	15%	23%	45%
D.	77%	45%	15%	20%	8%	35%
E.	54%	40%	8%	25%	38%	35%
F.	54%	45%	19%	25%	27%	30%
G.	77%	55%	8%	10%	15%	35%
H.	35%	40%	8%	10%	58%	50%
I.	77%	50%	8%	15%	12%	35%
J.	81%	60%	8%	5%	12%	35%

* Number of Respondents: High Level of Strain Group = 26, Low Level of Strain Group = 20.

The respondents in both groups used an average of 2.4 services
each. This is broken down as follows in the high level of
strain group:-

Table 15

Number of services used by high level of
strain group

1 respondent used 0 services
2 respondents used 1 service
11 respondents used 2 services
7 respondents used 3 services
4 respondents used 4 services

45

In the low level of strain group:-

Table 16

Number of services used by low level of
strain group

---

4 respondents used 1 service
3 respondents used 2 services
6 respondents used 3 services
1 respondent used 4 services
1 respondent used 5 services

In the high level of strain group 1 did not respond the this

section and 5 did not respond in the low level of strain

group. There is not any significant difference in the

distribution of the number of services used in the two groups.

4.5. Correlations.

Correlation coefficients were computed from the individual

total scores in the *Carer Strain Index* in comparison with

their corresponding scores from the *OARS Social Resource Scale*

and the *Formal Services Questionnaire*. Additional correlation

coefficients were computed by comparing the same score in the

Carer Strain Index with the corresponding scores from key

sections of the *OARS Social Resource Scale*.

The computations carried out using the total scores of

individuals in the *Carer Strain Index* and the corresponding

individual totals in the *OARS Social Resource Scale* (Appendix J) resulted in a correlation coefficient of -0.5 indicating a moderate negative relationship between individual responses to part A and part B of the questionnaire. The correlation coefficient of -0.5 means that as the level of strain decreased as indicated by responses to the *Carer Strain Index* there was an increase in avaiability of and satisfaction with social resources as indicated by responses to the *OARS Social Resource Scale.*

The individual scores to the questions "Is there someone who would give you any help at all if you were sick or disabled?" and "Is there someone who would take care of you as long as needed, or only for a short time, or only someone who would help now and again" from the *OARS Social Resource Scale* were compared with the corresponding individual scores from the *Carer Strain Index* (Appendix K) the resulting correlation coefficient was -0.2. This shows a slight trend towards a negative correlation between the level of strain as shown by responses to the *Carer Strain Index* and the questions in the *OARS Social Resource Scale* concerned with availability and duration of help in times of sickness but it is not statistically significant.

The questions that dealt with the respondents satisfaction with their informal social resources were also considered. The individual scores to the questions "Do you find yourself

feeling lonely quite often, sometimes or almost never?" and "Do you see your relatives and friends as often as you want to or are you somewhat unhappy about how little you see them?" from the *OARS Social Resource Scale* were taken as a separate group. The correlation coefficient between the scores in this group and the corresponding individual scores in the *Carer Strain Index* was computed (Appendix L) and showed a correlation coefficient of -0.6. This indicates a moderately strong negative correlation showing that with an increase in carer strain there is a significant tendency towards reduced satisfaction with informal social resources.

A fourth correlation was carried out taking the individual scores from part A of the questionnaire and the corresponding individual scores from part B omitting the scores from the questions " Do you find yourself feeling lonely quite often, sometimes, or almost never?" and "Do you see your relatives and friends as often as you want to, or are you somewhat unhappy about how little you see them?". That is to say the questions indicating satisfaction with contact were omitted from the computation. A correlation coefficient of -0.3 resulted indicating trend towards a higher number of potential contacts and actual contacts within the low level of strain group than within the high level of strain group.

Taking the total scores of individual respondents in *Carer Strain Index* and the corresponding individual totals in the

Formal Services Questionnaire (Appendix M) the correlation coefficient was computed as 0.04. This result indicated that there was no significant relationship between the level of strain expressed by respondents and the level of satisfaction they expressed with the formal services they used.

Chapter 5

Discussion

The literature indicated the probability of a correlation between carer strain or the percieved burden of care and the quantity and quality of formal and informal social networks available to the primary carer. This has been borne out to a limited extent in the survey. A moderately strong relationship was found between the expressed level of carer strain and the size, frequency of contact with and quality of the informal support network. No significant difference was shown between the percieved level of carer strain and the availability, use of and satisfaction with formal services.

5.1. Informal Networks.

The data show a moderately strong relationship between satisfaction with the carers' informal support networks and the level of strain experienced. The quality of the informal network, however, as measured by the degree of satisfaction expressed by the carer, was shown to be a stronger indicator of percieved carer strain than network size.

As a whole, the sample surveyed did not appear to be socially isolated. In the high strain group and the low strain group the majority of respondents reported frequent or regular contact with family and friends. Both groups showed a fairly high level of potential and actual contact. All members of the low strain group reported at least one contact with family or friends during the previous week, compared with two respondents in the high strain group who reported no personal contact with family or friends in the previous week. The majority in both groups reported multiple contacts during the previous week.

The results showed a slight trend for the high strain group to have fewer potential and actual contacts than the low strain group. The group of carers who showed a high level of strain as measured by the *Carer Strain Index* tended to express frequent or more than occasional feelings of loneliness and some unhappiness about how infrequently they saw their family or friends.

Although the size of informal networks appeared to be slightly related to the level of strain experienced, the level of satisfaction expressed in relation to informal networks showed as a much stronger indicator. The difference in strength between these two relationships, strain related to size of network and strain related to satisfaction with network, is indicated by the differing correlation coefficients. The

coefficient for strain in relation to the size of the network, of -0.3, compared with a coefficent of -0.6 for strain in relation to satisfaction with network.

It appears from the results of this survey that the size of the informal network has an effect, but, at least where carers are not socially isolated, the degree of satisfaction with the informal network is a more significant indicator of carer strain or percieved burden of care.

It might be suggested that contact with informal networks may, in some circumstances, cause less rather than more satisfaction. Frequent contact by a family member, for example, may be regarded as interference and thus decrease satisfaction and increase strain. A detailed examination of network quality would be required to test the effect of different types of contact.

5.2. Formal Networks.

The data show the high level of strain group as reporting a slightly greater level of satisfaction with formal services than the low level of strain group. The difference is not statistically significant however. Individual scores in the *Carer Strain Index* and the corresponding individual scores in

the *Formal Services Questionnaire* show a correlation

coefficient of only +0.04.

One item shows an interesting departure from this overall

trend. The high strain group indicated a higher level of

satisfaction than the low level of strain group in response to

all Formal Services Questonnaire items except item H, (I am

able to make suggestions about services). The low strain group

showed a slightly higher level of satisfaction on this item

40% (8) showing satisfaction, than the high strain group,

where 35% (9) showed satisfaction.

In response to item D (Service providers take my wishes into

account), 77% (20) of the high strain group and 45% (9) of the

low strain group expressed satisfaction. More respondents in

the high strain group expressed satisfaction in response to

this item. Responses to item G (I have a good working

relationship with service providers), showed similar responses

77% (20) expressing satisfaction in the high level of strain

group and 40% (8) of the low level strain of group. There is,

however, a marked difference of 42% (11) between the responses

of the high level of strain group to items D and G and this

group's responses to item H. It would be expected that, where

the carer's wishes are perceived as being taken into account

and a good working relationship is seen to exist, the carer

would feel able to make suggestions about the services they

receive. The results, however, do not bear out this

expectation.

The fewer respondents expressing satisfaction in the low strain group in response to items D and G may suggest that carers in this group are able to be more critical, perhaps more able to reflect on the adequacy and appropriateness of formal services and more demanding in what they ask from service providers. Perhaps carers under greater stress find it more difficult to make suggestions or to think of suggestions about services. Perhaps where strain is considerable, it is difficult to criticise available help or appear to demand more than is offered. Carers under less stress may also have more energy to think of ways in which their task might be lightened or improved.

It is also of interest that item H (I am able to make suggestions about services), not only shows the smallest number of responses in the high level of strain group indicating satisfaction but also shows the highest number of undecided or no response answers in both groups. Eleven of the 46 respondents, or 24%, did not respond to this item and 14 of the 46, or 30%, were undecided. In the individual groups as 58% (15) in the high strain group and 50% (10) in the low strain group, which is markedly different from the undecided responses to items D and G. In item D (Service providers take my wishes into account), only 8%, (2), of the high level of strain group were undecided. In item G (I have a good working relationship with service providers), 15%, (4), of the high

level strain group were undecided. The low level strain group
showed 35%, (7), undecided for both of these two items. It is
difficult to see why the difference should occur, particularly
with the high level of strain group where the difference is
large. It may be speculated that service providers are seen as
separate from services. That is to say, the service provider
is seen as the person who performs the hands on work in the
carer's home whereas the service is that which is outside the
home and imposed by a distant bureaucracy. Thus, although
carers express satisfaction with their day to day interaction
with service providers who come into their homes, they perhaps
do not feel in control of the type of service that is
provided.

Seven respondents from the total sample did not respond to any
of the final ten items in the questionnaire. Of these, 2 were
from the high level of strain group and 5 from the low level
of strain group. From the high level of strain group one made
the comment, "I have never had any service help other than
Woodhouse Centre"; the other made no comment. In the low level
of strain group, 4 of the 5 who did not respond to this
section made comment. One reported having insufficient
experiences to answer adequately and another said "I do not
use any service". One remarked that due to health problems she
was unable to complete the whole questionnaire. The fourth
person in this group wrote a letter expressing satisfaction
with a range of service the she had received prior to her

husband's death and states very clearly that such services

made it possible for her to care for her husband at home.

It appears that the sample contained many individuals with

experience of formal services who were able to respond about

their level of satisfaction. This level of ability to respond

is at variance with Twigg, Atkin and Perring's comments about

the general population of carers in the United Kingdom:-

*One of the difficulties of asking carers about the
effectiveness of support is that so many carers have little or
no experience of services to discuss.(1991 p.76).*

With few exceptions the resopondents to part C of the

questionnaire, however, expressed satisfaction with formal

services, supporting what Twigg, Atkin and Perring say about

service users:-

*Their comments, where they have received services, are often
limited to a grateful account.(1991 p. 76).*

It is therefore possible to conclude that carers are generally

grateful for formal services that reduce their workload and

make it possible for them to continue in their caring role,

but that services are accepted somewhat uncritically.

It is recommended that the following be implemented:-

. the providers of formal services be trained and
  encouraged to support and strengthen informal networks

. formal service providers be encouraged to work with
  carers to devise ways in which informal networks may be
  strengthened and if appropriate revitalised

. formal services work with carer groups to develop
  strateges whereby formal services and informal networks
  complement each other.

5.3. Limitations.

5.3.1.Systematic Sampling.

The systematic sampling method was used because it was necessary to use subjects who met the criterion of being primary carers of dependent aged persons. The sample was taken from the Southern Tasmania Aged Care Assessment Team's records of clients who had been assessed as eligible for long term nursing home care or residential respite care in a nursing home. This raises the question of the validity of the sample: do the carers of aged persons who have been assessed by A. C. A. T. as being eligible for nursing home care accurately represent the primary carer population in Southern Tasmania?

Alternative methods of locating primary carers would have involved using the records of organisations or services such as the "Carers Association" or community health services and would have resulted in a sample that included only those known to the organisations or services. The use of a sample of primary carers known to any organisation or service has at least an equal potential for bias as that in the chosen method.

A preferable method would have been to take a sample from the total primary carer population but the difficulties involved

in locating that population make such an approach impractical in a small survey.

5.3.2. The Questionnaire.

The individual reliability and validity of the *Caregiver Strain Index* and the *OARS Social Resource Scale* has been established, as indicated in Chapter 3. The reliability and validity of the *Formal Services Questionnaire* has not been formally established. The reliability and validity of the three instruments when used as a battery has not been tested.

The method of administration by questionnaire may have resulted in less comprehensive and complete answers than had it also made use of personal interviews. A combination of questionnaire and interview could have provided some additional information about the factors influencing quality of informal networks and satisfaction with formal services.

5.3.3. Comments.

It would have been useful to add a section to the questionnaire to invite comment from respondents. The comments that were made by a small number of the respondents gave

additional information about their circumstances that would

not have been available had they merely completed the

questionnaire.

5.3.4. Demographic information.

The collection of more demographic information may have been

useful e.g. age, sex, general health status of carers and

those for whom they are caring. The study may not have

controlled well for the possible influence of such variables.

5.3.5. Instruments.

The instruments had some limitations, resulting from the

choice made to use those that were short and as nonintrusive

as possible.

5.4. Recommendations for further research.

This study has examined the relationships between the level of

strain experienced by carers and their formal and informal

social support networks. An examination of more specific

factors, for example, the effect of the carer's physical and

mental health, or of the strengths and weaknesses of

particular formal services, could lead to deeper understanding

of factors influencing carer strain and thus assist in prevention of elder abuse.

5.4.1. Specific formal services.

The current study asked about general satisfaction with formal services. It is suggested that individual services could be examined separately, so that a more complete understanding can be gained of which services are most helpful in the alleviation of carer strain.

5.4.2. Additional variables.

Support networks may correlate with a number of other variables and it would be possible to use these to reflect a range of correlates. Some examples are:-

a). The level of dependence existing between carer and cared for person
b). Carer psychopathology
c). The physical and mental health of the carer and the cared for person
d). Family dysfunction
e). The relationship between carer and cared for (spouse, relative, non-relative, employee)

These factors may have a bearing on the level of strain experienced by carers and their use of and satisfaction with informal and formal support networks.

5.4.3. Access to services.

This study used a sample of the population who by definition

had access to services. Thus their experience may be different

from that of the general population. In order to test the

availability of and access to services it is suggested that a

general survey of the population of Southern Tasmania over the

age of seventy could be made to determine:

a) The number who have primary carers
b) The types of informal social networks they have
c) The satisfaction with their social network
d) Carers knowledge of available service
e) What services they have access to
f) Whether they have been refused services
g) Whether they are satisfied with services received

A survey of the general population should provide a more

comprehensive picture of the relationship between carer strain

and the availability of and satisfaction with formal and

informal social networks. It would also give a clear

indication of the bias, if any, of the current study.

5.4.4. Service provision criteria.

It is suggested that an examination of the criteria used to

decide whether formal services are provided could be made.

Such an examination should take particular note of the

presence or absence of a primary carer and whether or not the

primary carer's needs, other than physical needs, are being

taken into account.

5.5. Conclusion.

The aim of this study was to explore the degree of relationship between the level of strain experienced by primary carers of aged persons and their satisfaction with available informal and formal support networks. It was proposed that, if a low level of strain experienced by carers was strongly related to a high level of satisfaction with formal and informal support networks, manipulation of networks could be a means of reducing the potential abuse of aged persons.

The results of the study did not show a significant difference between the level of satisfaction with formal services and the level of strain experienced. A high level of service use was indicated; 33 of the 46 respondents reporting use of more than one formal service and a further 6 reporting use of one service. This may suggest that currently existing formal services are at least adequate in providing basic material support.

The study showed a moderately strong trend towards a decrease in the level of strain reported as the level of satisfaction with informal support increased. It was also shown that with an increase in size of the informal network and frequency of contact with its members there was a moderate trend towards a decrease in the level of strain experienced.

Thus the results of the study are somewhat mixed, showing a moderately strong relationship between the level of strain and informal networks but no relationship between the level of strain and formal services.

Closer examination of informal networks, their composition, quality and contribution to the carer's task could suggest ways to enhance and maintain informal networks. A thorough understanding of the strengths and weaknesses of informal support networks could provide the basis for the development of formal support services designed to complement them, providing a means of reducing carer strain and reducing the potential for abuse of the elderly.

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QUESTIONNAIRE

PART A.

THIS IS A LIST OF THINGS THAT OTHER PEOPLE HAVE FOUND TO BE DIFFICULT IN CARING FOR SOMEBODY.
PLEASE INDICATE WHICH OF THESE APPLY TO YOU. (PLEASE CIRCLE *YES* IF THEY APPLY TO YOU OR CIRCLE *NO* IF THEY DO NOT).

Sleep is disturbed (eg. because person cared for is in and out of bed or wanders at night)	YES	NO
It is inconvenient (eg. because caring takes so much time)	YES	NO
It is a physical strain (eg. because of lifting in and out of a chair, effort or concentration required)	YES	NO
It is confining (eg. helping restricts free time or cannot go visiting)	YES	NO
There have been family adjustments (eg. because helping has disrupted routine; there has been no privacy)	YES	NO
There have been changes to personal plans (eg. could not go on holiday, had to give up outside interests)	YES	NO
There have been other demands on my time (eg. from other family members)	YES	NO
There have been emotional adjustments (eg. because of severe arguments)	YES	NO
Some behaviour is upsetting (eg. because the person cared for is incontinent or has trouble rembering things or accuses people of taking things)	YES	NO
It is upsetting to find that the person being cared for has changed so much from his/her former self (eg. seems a different person from the one you have always known)	YES	NO
There have been work adjustments (eg. because of having to take time off or give up paid employment or voluntary work)	YES	NO
It is a financial strain	YES	NO
Feeling completely overwhelmed (eg. because of worry about the person being cared for or concerns about how you will manage)	YES	NO

PART B

THESE ARE SOME QUESTIONS ABOUT YOUR FAMILY AND FRIENDS. WOULD YOU PLEASE
ANSWER THEM IN THE WAY INDICATED IN EACH QUESTION.

Who of the following live with you (please circle YES or NO)

* No one	YES	NO
* Husband or wife	YES	NO
* Children	YES	NO
* Grandchildren	YES	NO
* Parents or parent	YES	NO
* Grandparent or parents	YES	NO
* Brothers and/or sisters	YES	NO
* Other relatives	YES	NO
* Unrelated person/people	YES	NO
* Other (specify)	YES	NO

How many people do you know well enough to visit in their own homes?
(Circle one of the following)

* Five or more.   * Three to four.

* One or two.   * None.

How many times did you talk to someone - friends, relatives or others -
on the telephone in the past week (either you called them or they called
you)? (Circle one of the following)

* Once a day or more.   * Two to six times.

* Once.   * Not at all.

How many times in the past week did you spend some time with someone who
does not live with you; that is, you went to see them, or they came to
visit you or you went out to do things together?

* Once a day or more.   * Two to six times.

* Once.   * Not at all.

Do you have someone you can confide in? (Please circle YES or NO).

*YES   *NO

Do you find yourself feeling quite lonely? (please circle one of the
following)

* Quite often.   * Sometimes.   *Almost never.

Do you see your friends and relatives as often as you want to, or are
you somewhat unhappy about how little you see of them? (Please circle
one of the following)

* As often as I want to.

* Somewhat unhappy about how little I see of them.

Is there someone who would give you any help at all if you were sick or
disabled? (Please circle one of the following).

* Yes.   * No-one willing AND able to help.

If you answered "Yes" to the previous question please answer the next
two, if you answered that there is no-one willing AND able to help pleae
move on to PART C.

Is there someone who would take care of you (Please circle one of the
following)

* ..as long as needed?

* ..for a few weeks to six months?

* ..now and again? (eg. take you to doctor or fix lunch)

Is that person a relative, friend or other? (Please circle one of the
following)

* Relative.   * Friend.   * Other (Specify............).

PART C.

THE FOLLOWING QUESTIONS ARE ABOUT COMMUNITY SERVICES

Please circle which of the following services you know about:-

* Community Nursing   * Home Help   * Handyperson service

* Meals on Wheels   * In-home respite   * Residential respite

* Community Transport

Please circle any of the following services you are using or have used:-

* Community Nursing   * Home Help   * Handyperson service

* Meals on Wheels   * In-home respite   * Residential respite

* Community Transport   * Other (Specify............................)

Please circle the number that best describes your response to the
following statements (1 = Strongly agree. 2 = Agree. 3 = Undecided.
4 = disagree. 5 = strongly disagree):-

I would recommend the services I use to other carers.   1..2..3..4..5.

The services I use meet my needs.   1..2..3..4..5.

The Services I use fit in with my schedule.   1..2..3..4..5.

Service providers take my wishes into account.   1..2..3..4..5.

I have input into what services are provided.   1..2..3..4..5.

I am able to negotiate changes in services.   1..2..3..4..5.

I have a good working relationship with service providers.1..2..3..4..5.

I am able to make suggestions about services.   1..2..3..4..5.

The services help to reduce my workload.   1..2..3..4..5.

I would have difficulty managing without the services.   1..2..3..4..5.

THANK YOU FOR COMPLETING THE QUESTIONNAIRE.

APPENDIX D.
UNIVERSITY OF TASMANIA ETHICS COMMITTEE
(HUMAN EXPERIMENTATION)

APPLICATION TO UNDERTAKE AN INVESTIGATION INVOLVING HUMAN SUBJECTS

Please type this application and return it to the Secretary,University Ethics Committee (Human Experimentation), Office of Research, Hobart Campus.

1.   TITLE OF PROPOSED INVESTIGATION
  THE RELATIONSHIP BETWEEN THE BURDEN OF CARE AND FORMAL AND INFORMAL SUPPORT NETWORKS IN THE PREVENTION OF ELDER ABUSE: A CORRELATIONAL STUDY.

2.   APPLICANTS (Chief Investigator first)
  1. Dr. Carey Denholm
    2. D. John Hensley   (Special Project for Master of Education)

3.   TEACHING/RESEARCH
    Is the proposed investigation for teaching or research?
  Research

4.   AIMS
    Please give a concise description of the aims of the investigation.
  To investigate if there is a significant correlation between the perceived care burden experienced by primary carers and the availability and appropriateness of support networks.

5.   JUSTIFICATION
    The literature makes it clear that no one cause of elder abuse can be isolated and thus there is no one way of dealing with the problem. It is, nevertheless, strongly indicated that certain common factors occur in a wide range of situations in which abuse occurs or is seen as likely to occur. These factors are on the one side the perceived burden of care experienced by the primary carer and on the other the availability and appropriateness of the carer's informal support networks and formal services. It is also strongly suggested that good informal support networks promote appropriate use of formal services. If this can be shown it follows that an appropriate approach to the prevention of elder abuse lies in the development and promotion of coordinated support networks that interactive and complementary.

6.   BRIEF DESCRIPTION OF THE INVESTIGATION
    Questionnaires seeking carers perceived burden, informal and formal support will be administered to 50 primary carers (questionnaires appended as Appendix B).

OFFICE USE ONLY
INTERIM APPROVAL
Chairperson   Date   Approved for period......to......

FINAL APPROVAL
Chairperson   Date   Approved for period......to......

8.   FUNDING
Will this investigation proceed only if an external grant is obtained? Yes/No
NO.

If YES, what is the name of the grant awarding organisation?...................

9.   REVIEW OF ETHICAL CONSIDERATIONS
Has this protocol previously been submitted to the Ethics Committee? Yes/No
NO

10.   RESEARCH PROCEDURES
Give details of the experimental plan and procedures which will be followed.

1. A systematic sample of 50 primary carers will be taken from the records of the Southern Region Assessment Team.

2. All members of the sample will be contacted by telephone and asked if they are willing to take part in the study (copy of wording to be used in this contact is attached as Appendix A).

3. Questionnaires will be mailed to those who agree to take part together with a stamped addressed envelope for the return of the questionnaire (copy of questionnaire is attached as Appendix B).

4. A regression analysis of the returned questionnaires will be carried out.

11.   SUBJECTS AND SELECTION
Intended experimental group (age group, sex, state of health, and other special characteristics:
eg. children students, persons in dependent relationships).
Adult primary carers i.e. carers residing with the elderly person they are caring for.
Likely to be middle aged or elderly.
Male and female.

Selection procedure
A systematic sample in accordance with part 1 and 2 of section 10.

12.   SOURCES OF PERSONAL INFORMATION
Personal information is information which allows the identification of an individual. Are you
obtaining data containing personal information from any government agency? Yes/No
Yes. (Note: Names and addresses of members of sample will be obtained but the data received from the participants will be anonymous. No identifying information will appear in the study.)

If YES, state (i) the names of these agencies and (ii) the nature of this data.
(1) Southern Region Assessment Team, Dept of Community and Health Services.
(2) Names and addresses of members of sample.
Explain the justification for obtaining personal information.
To make initial contact and mail questionnaires in order to obtain data.

13.   POTENTIAL RISKS
Please describe any possible physiological or psychological risks associated with this
investigation.
There are no physiological risks. It is unlikely that there will be any psychological risks.

14. PRE AND POST CONTACT

Describe the steps to be taken to explain the procedures to the subjects and, if appropriate, procedures which will establish the well-being of the subjects when the investigation is concluded.

Telephone contact will be made before questionnaires are sent to ask if members of sample are willing to take part in the study and to explain what is required (see Appendix A).

15. REMUNERATION

Will any financial remuneration or other reward be offered to the subjects for their participation, other than reimbursement of out of pocket expenses? Yes/No

NO

16. CONFIDENTIALITY OF RECORDS

How will confidentiality of records be maintained?

Records will be kept under lock and key at the office of the Southern Region Assessment Team and all identifying material will be destroyed when the completed questionnaires are received at that office (see Appendix C).

17. DRUG USE STATUS

Are drugs directly or indirectly involved with the procedures? Yes/No

NO

If YES, please give details, including information on known or suspected adverse effects.

18. BLOOD OR TISSUE SAMPLING

Do the procedures involve blood or tissue sampling? Yes/No

NO

If YES, please give details.

19. OTHER ETHICAL ISSUES

Are there, in your opinion, any other ethical issues raised by this investigation? Yes/No

NO

If YES, please give details.

20. DRAFT CONSENT FORM

A draft consent form is attached.
(Appendix D).

21. STATEMENT OF SCIENTIFIC MERIT

The Head of Department is required to sign the following statement:

idered and is sound with regard to its merit and methodology.

13|9|95

....
Date

22. CONFORMITY WITH NHMRC GUIDELINES

The Chief investigator is required to sign the following statement:

I have read and understood the NHMRC "Statement on Human Experimentation and Supplementary Notes". I accept that I, as Chief Investigator, am responsible for ensuring that the investigation proposed in this form is conducted fully within the conditions laid down in the NHMRC Statement.

....
Signature of Chief Investigator   Date

1/8/95 .

23. SIGNATURE OF OTHER APPLICANTS

31-7-95

....

....

MEMORANDUM .

TO: Team Leader, Southern Region Assessment Team.

FROM: John Hensley.

SUBJECT: Permission to contact clients for study purposes.

DATE: 31st. July 1995.

As part of my studies at the University of Tasmania for a Master of Education in Counselling and Development I am undertaking a study to investigate the relationship between the burden of care and formal and informal support networks in the prevention of elder abuse. The University supervisor for the project is Dr. Carey Denholm.

I seek permission to take a systematic sample of 50 primary carers from the records of the Southern Region Assessment Team.

I attach hereto a copy of my submission to the University of Tasmania Ethics Committee (Human Experimentation) together with appendices. Appendix A is a copy of the wording to be used in the initial telephone contact with prospective subjects. Appendix B is a copy of the instrument to be used. Appendix C is the procedure to be used to ensure confidentiality.

Thank you for your consideration of this matter.

John Hensley

MEMORANDUM

Southern Region Aged Care Assessment Team

To: John Hensley

From: Lynn Cohen, Team Leader

Subject: Permission to contact clients for study purposes

Date: 31 July, 1995

File Reference:

Thank you for the information regarding your proposed study. As we have discussed, I fully support the study and give permission for you to contact clients using the procedures outlined in your document.

Good luck with your research.

TELEPHONE COMMUNICATION.

Hello......... My name is John Hensley, I am an Assessor with the Southern Region Assessment Team and am also a student undertaking a Master of Education Studies at the University of Tasmania.

As part of my study I am doing a project to get an understanding of the relationship between any stress experienced by people caring for others in their own home and the availability of and satisfaction with formal and informal support.

I would be most grateful if you would allow me to take a few minutes of your time to explain a little about the project and then to ask you if you would be prepared to help me in this by allowing me to send you a questionnaire to complete.

I am contacting 50 primary carers. The information that I get back from them will be analysed and then I will write a report from the results. No names will be used in the report and nothing will appear that can identify individuals. I will enclose with the questionnaire a copy of the procedure that will be used to ensure confidentiality.

The questionnaire will have three parts. The first part seeks to find out how you feel about being a carer and the way it affects your life. You will be asked to answer "yes" or "no" to the questions. The second and third part will ask you about support and practical help you have available to you and how useful you find it. You will be asked to choose between a number of set answers to each question.

It is likely to take you no more than fifteen or twenty minutes to complete the questionnaire.

I will enclose with the questionnaire a stamped envelope addressed to me for you to return it.

I hope that from this it will be seen what helps to reduce some of the strain of being a carer.

Do you have any questions?

May I send you a questionnaire?

If the person is unprepared to accept a questionnaire:-
That's fine. Thank you letting me talk to you about it.

If the person is prepared to accept the questionnaire:-
Thank you very much. I will mail the questionnaire to you today. If when you receive it you have any questions please contact me on 781288. Would you please post it back to me in the envelope provided by ....(*five days after telephone contact*). If I haven't received it by ...(*eight days after telephone contact*) would you mind if I contact you again to check if you have sent it?

Thank you very much for your time.

CONFIDENTIALITY.

Procedure for ensuring that no identifying information is included in study.

1. A list of participants in the study will be prepared from S.R.A.T. records using a systematic sampling method. The list will be numbered from 1 to 50.

2. The stamped addressed envelopes enclosed for the return of questionnaires will be given corresponding numbers.

3. As each returned questionnaire is received its numbered envelope will be checked against the list but the envelope will not be opened.

4. At the due date for the return of questionnaires the list will be checked for any unreturned questionnaires and telephone contact will be made those who have not returned their questionnaire to remind them.

5. When all questionnaires have been returned or one week after the date of the reminder call has been made the numbered list will be destroyed.

6. A clerical assistant who has not had access to the numbered list will open the envelopes, give the contents to the researcher and destroy the envelopes.

7. No identifying information should be on the completed questionnaires, but should such information appear it will be deleted by the researcher before the data is processed.

Thank you very much for agreeing to complete the attached questionnaire. Would you please return the completed questionnaire in the enclosed stamped addressed envelope by Monday 28th. August 1995.

Many thanks

John Hensley.

A = How many people do you know well enough to visit in their own homes?
   Scores: 3 = Five or more, 2 = Three to four, 1 = One or two, 0 = none.
B = How many did you talk to someone – friends, relatives, others – on the 'phone in the past week? Scores: As for A above.
C = How many times in the past week did you spend some time with someone who does not live with you; that is, you went to see them, or they came to visit you or you went out to do thing together?
   Scores: As for A and B above.
D = Do you have someone you can canfide in? Scores: 1 = Yes, 0 = No.
E = Do you find yourself feeling quite lonely? Scores: quite often = 1, sometimes = 2, almost never = 3.
F = Do you see your relatives and friends as often as you want to or are you somewhat unhappy about how little you see of them? Scores: 2 = As often as wanted, 1 = somewhat unhappy.
G = Is there someone who would give you any help at all if you were sick or disabled?
   Scores: 1 = yes, 0 = no.
H = Is there someone who would take care of you...Score: 3 = as long as needed, 2 = up to 6 months, 1 = now and again.
Tot. = Individual total scores on *Social Resource Scale*.
C.St. = Individual total scores on *Carer Strain Index*.

A	B	C	D	E	F	G	H	Tot	C.St.
2	1	0	1	1	1	0	0	6	12
1	2	1	0	1	1	0	0	6	12
2	2	1	1	1	1	1	1	10	12
1	2	1	0	1	1	0	0	6	12
3	2	2	1	2	1	1	1	13	11
2	2	3	1	2	1	1	1	13	11
0	0	0	0	2	1	1	3	7	10
1	0	0	0	1	1	1	3	7	10
2	3	1	1	2	1	0	0	10	10
2	3	1	1	2	2	1	1	11	10
2	0	0	1	2	2	1	3	11	10
3	3	2	1	2	1	1	1	14	10
3	0	3	1	2	2	1	1	13	10
2	3	2	1	3	1	1	1	14	10
3	2	2	1	2	1	1	1	13	9
3	2	1	1	2	1	1	1	12	9
1	3	0	1	2	0	0	0	7	9
0	2	3	1	2	1	1	3	13	9
3	2	0	1	2	1	1	1	11	9
3	2	1	1	3	2	1	3	16	9
3	2	0	1	1	1	0	0	8	9
1	2	0	1	2	1	0	0	7	8
1	1	2	1	1	1	1	3	11	7
2	3	3	1	2	2	1	3	17	7
3	3	1	1	3	1	0	0	12	7
2	2	1	1	3	2	1	1	13	7
3	2	3	1	2	2	0	0	13	6
3	2	2	1	3	1	0	0	12	5
3	2	0	1	3	1	0	0	10	5
2	2	1	1	1	2	1	1	11	5

A	B	C	D	E	F	G	H	Tot	C. St.
3	2	2	1	2	2	1	1	14	5
3	2	2	1	3	2	1	3	17	5
0	2	1	1	3	2	0	0	9	5
1	3	3	1	3	1	1	1	14	5
3	3	0	1	3	1	1	3	15	4
3	3	0	1	2	1	1	3	14	4
0	2	2	1	2	2	1	3	13	4
3	2	2	1	3	2	1	1	15	3
2	2	0	1	3	2	1	1	12	2
0	2	2	1	2	2	1	1	11	2
3	3	2	1	2	2	0	0	13	2
3	2	2	1	2	2	2	1	16	0
2	3	1	1	1	1	1	1	11	0

```
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Correlation Coefficient = -0.48
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Total Sick Help. Q.G + Q.H	Total *Carer Strain* *Index.*
0	12
0	12
2	12
0	12
2	11
2	11
4	10
4	10
0	10
2	10
4	10
2	10
2	10
2	10
2	9
2	9
0	9
4	9
2	9
4	9
0	9
0	8
4	7
4	7
0	7
2	7
0	6
0	5
0	5
2	5
2	5
4	5
0	5
2	5
4	4
4	4
4	4
2	3
2	2
2	2
0	2
4	0
2	0

Correlation Coefficient = -0.2

85

Level of Satisfaction Q.E + Q.F	*Carer Strain Index* Individual Totals
2	12
2	12
2	12
2	12
3	11
3	11
3	10
2	10
3	10
4	10
4	10
3	10
4	10
4	10
3	9
3	9
2	9
3	9
3	9
5	9
2	9
3	8
2	7
4	7
4	7
5	7
4	6
4	5
4	5
3	5
4	5
5	5
5	5
4	5
4	4
3	4
4	4
5	3
5	2
4	2
4	2
4	0
2	0

Correlation Coefficient = -0.6

86

Formal Services Questionnaire	Carer Strain Index
27	12
21	12
30	12
14	12
28	11
28	11
29	10
29	10
27	10
28	10
24	10
17	10
29	10
26	9
30	9
30	9
26	9
28	9
30	9
29	9
17	8
29	7
28	7
28	7
20	6
16	5
16	5
22	5
30	5
30	5
24	5
30	4
27	4
30	3
29	2
10	2
29	2
30	0
30	0

Correlation Coefficient +0.04