A qualitative evaluation of a bereavement service: An analysis of the experiences of service consumers and providers

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A QUALITATIVE EVALUATION OF A BEREAVEMENT SERVICE:

AN ANALYSIS OF THE EXPERIENCES OF SERVICE CONSUMERS AND PROVIDERS.

BY

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Dip.O.T. B.App.Sc. O.T.

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ABSTRACT

Human service evaluation has become an important consideration in service delivery due to an increased demand for accountability by funding bodies. Time constraints, financial constraints and political interests, however, influence the implementation and outcomes of evaluation projects. As a result, quantitative methods are most frequently used. Information obtained as the result of quantitative studies which are politically expedient may present a superficial view of a program and overlook the fundamental issues of program delivery which are important to participants. Identification of the valued aspects of program involvement and areas of unmet need from participants' perspectives may remain unknown as a result of seeking information on predetermined and routine program processes in order to maintain the 'status quo'.

The purpose of this study was to demonstrate the use of qualitative research methods to evaluate a human service program, adopting a symbolic interactionist approach in which program participants were acknowledged as expert informants who were capable of identifying valued aspects of the program. The interactive milieu of the service as opposed to the organisational environment was the context for evaluation in which data was collected by a process of in-depth face-to-face interviews involving both consumers' and providers' of the program.

The context of the study was a bereavement support program provided by Silver Chain Hospice Care Service, Perth, Western Australia.

Thirty current and past consumers of bereavement support services and ten nurses and ten volunteers who provided bereavement support were involved in providing information on
their experiences with the program. A phenomenological approach to data collection and a content analysis procedure identified emergent themes for each group of participants. Program processes related to valued help activities, their value to participants, and influences and barriers to their implementation were identified in relation to each emergent theme. Elements of a valued bereavement program from the perspectives of each group of participants were then stated. This information allowed the organisation to address issues of safeguarding valued activities while also addressing the influences and barriers to their implementation which emerged from participants' descriptions.
DECLARATION

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education: and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.
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CHAPTER 1. INTRODUCTION

1.1. INTRODUCTION TO THE STUDY

This study will demonstrate the use of qualitative research methods in human service evaluation to identify key areas for program development. This will be accomplished by undertaking a qualitative evaluation of a bereavement program to provide some qualitative insights into the individual, personal experiences of consumers and providers of the program. By a process of face-to-face in-depth interviews with consumers and providers of the service, qualitative data will be obtained to provide a deeper understanding of the program and to determine what meaning the program has for participants and what participants perceive to be its usefulness. The interactive environment rather than the organisational environment of human service delivery will be the study context and the study will value the contributions of participants in the program as expert informants who can supply accurate assessments of the usefulness of the program from their perspectives.

1.2. BACKGROUND TO THE STUDY

Recent years have seen a significant growth in the number of human service evaluations undertaken in Western Australia. Funders' demands for accountability in terms of effective implementation and outcomes of services drive many of Western Australia's evaluation programs as service providers engage in a highly competitive drive to obtain the welfare dollar. Government funding of evaluation programs which are designed to prove the efficacy of services that support government policies, however, may be susceptible to bias in methodology and reporting. The popular use of quantitative methods in program evaluation reflects societal expectations of productivity and
effectiveness and the utilitarian view of human service implementation held by society as a whole. In addition, the need to evaluate programs in order to help program administrators balance equity, efficiency and political feasibility, is determined by an uncertain environment in which financial resources, human resources, time and experience are frequently changing.

There is a danger that current evaluation practices in human services can become a series of research steps which are uniformly applied to various programs using methods which are expedient from a time and cost perspective. Participant surveys and satisfaction questionnaires are highly favoured by program administrators. These methods provide descriptive statistics on program implementation which are often highly subjective and superficial, however, the ability to survey large numbers of people and present information in a simple format which is easily interpreted by funders and administrators satisfies the need to demonstrate accountability. As the evaluation process is a powerful tool to enable political objectives to be fulfilled within organisations, survey questionnaires are particularly susceptible to manipulation. Evaluation results, therefore, may prolong the delivery of ineffective and undervalued services which may not reach the most needy target groups.

Evaluation methodologies must be carefully designed and implemented in order that ethical issues can be addressed in relation to evaluation purpose. If human services are indeed concerned with meeting human needs, then human service evaluations must also be concerned with providing information which is aimed at improving service delivery to meet those needs. Many ethical issues surround the implementation of evaluation practices. The funding of evaluations has already been referred to, however, another issue is the relative utility of evaluations which are conducted internally by a service
employee or externally by an 'independent' evaluator. Although no evaluator can come to an evaluation 'value free', it is important to consider the 'fit' between the evaluator and the program and explicate the purpose of the evaluation clearly so that the evaluation can be placed in context of the particular political climate surrounding the service at the time. Obtaining full and accurate information to enable a greater understanding of the problems of participants and allowing participants themselves to identify areas for service improvement may be an unrealistic ideal, however, this study intends to demonstrate that information of this nature can be obtained and that an independent evaluator operating at a grass roots level without becoming involved in an organisational hierarchy can obtain a valuable insight into the way a program operates and provide relevant information for future program development.

As human service evaluations are concerned with what is valued within human service programs, it is important to consider the values inherent in qualitative methodologies. The need to identify methods of obtaining information which are responsive to the needs of program participants to present information in their own way in order that the richness and complexity of their experiences with the program can be understood, acknowledges that participants themselves are experts in the evaluation process. The outcomes of their experiences with the program, therefore, are not measured against organisational goals and objectives, but gain relevance according to their personal frames of reference. The value of the program is allocated by them in relation to the parameters of their individual lifestyles. The other key issue in the method undertaken in this study is the inclusion of service providers in the evaluation process. This is based on a belief of the researcher that providers of services also share in the experience of the service with consumers. Because of the nature of many human services and their existential relevance for both consumers and providers, the interactive nature of the human service environment
demands that the experiences and needs of providers are also addressed when evaluating a service. In considering the healthy service environment as a unified whole which meets the needs of all participants, it is important to identify influences and barriers to service delivery from the perspectives of all participants, so that an holistic approach to service delivery can be addressed. This strategy has an empowering influence on both consumers and providers of the program by acknowledging the importance of their contributions in future decisions regarding service development.

How then can personally relevant information obtained from a diverse group of key informants be useful in terms of understanding the service as a whole and how can this be presented in such a way that administrators and funders will recognise as valid? The purpose of this study is to address these issues. An underlying assumption in undertaking this research is that there are common experiences shared amongst people who are involved in human service programs. It will be the intention of the researcher to identify shared experiences of participants and obtain participants' perspectives of the meaning and value of such experiences.

1.3, SELECTING A PROGRAM TO EVALUATE

The need for evaluators to conduct evaluations in an ethical manner and without bias in order that accurate information can be obtained for the benefit of human service program consumers and providers has been discussed. As this researcher's human service experience had been obtained mainly in the areas of health and disability services, and as the researcher had strong biases related to the way that services in these areas should be delivered to address consumer needs, other service areas were investigated. It was important, from the researcher's perspective that this study should not merely be
conducted for academic gain. A service was sought which perceived that it would value
the presentation of information in the way which this study intended. It was important
from the researcher's perspective that the organisation in which the evaluation would be
undertaken was community based and widely used by the general population of Western
Australia. It was also important that the researcher had no prior knowledge or experience
of the organisation and could come to the evaluation as free from bias as possible. This
would allow the evaluation method to be trialed in optimum circumstances.
Through informal inquiry and social networks, the researcher contacted Silver Chain
Hospice Care Service to determine if there was a need for any aspect of the service to be
evaluated. Communication with the Service Manager identified a need for an evaluation
of the bereavement follow-up program. Qualitative information was being sought about
the usefulness of the service for administrative purposes. A proposal to undertake such
an evaluation was then submitted to the Board of Management of Silver Chain Hospice
Service in April, 1993 and subsequently approved.

1.4. SIGNIFICANCE AND PURPOSE OF THE STUDY

The significance of this study was the intention of undertaking an interpretive approach to
evaluate a bereavement program so that the meaning of the program to participants could
be identified and its usefulness better able to be judged. An extensive literature review
had failed to identify the existence of similar research in this area. Using a qualitative
evaluation design allowed for information which was relevant to participants to be
revealed related to their beliefs and values concerning the program without controlling or
manipulating participants.
Bereavement is a state generic to all members of the community and there has been a significant increase in demand for formal services which support people during bereavement (Personal Communication, Hospice Care Service Manager, March 1993). As an increasing number of people access hospice services to meet the needs of their terminally ill family member, it was important to identify valued aspects of bereavement services from the perspectives of participants in the program. This had merit from both an individual preventative health perspective and a community wellness perspective. It was also important to identify perceived areas of unmet need to ensure that the service would continue to develop responsive programs. The intention of the research was not only to provide important information to be considered in the future development of bereavement support services, but also to develop a framework for a qualitative evaluation of a bereavement program and discuss the implementation of a similar approach to evaluate other human services.

1.5. STUDY OBJECTIVES

The objectives of this study were therefore:

* To demonstrate the use of a qualitative evaluation method to identify key areas for program development in the context of a bereavement program.

* To develop a framework for human service evaluation which had as its focus the experiences of participants related to their interactions with the service.

* To identify the meanings shared by consumers and providers in a bereavement program related to their experiences with the program.
To identify which interactions within a bereavement program were highly valued by consumers and providers.

To identify influences on, and barriers to, highly valued interactions.

1.6. RESEARCH QUESTION

What are the highly valued interactions within a bereavement program from the perspectives of consumers and providers of the program?
CHAPTER 2. LITERATURE REVIEW

The purpose of this literature review is to discuss evaluation practices, present literature on bereavement, and critique previous evaluations of bereavement programs.

2.1. INTRODUCTION TO EVALUATION

Evaluation is the application of social science research methods to answer questions about the operations and impacts of human service programs and can be defined as a systematic effort to determine the worth of a program provided to an identified population in pursuit of pre-determined outcomes. Worth may be defined as the achievement of specified outcomes; as costs of the services; as satisfaction with the service; or as combinations of more than one of these (Levine and Rosenberg, 1979).

There are three main uses for program evaluation namely:

* Improving the program by providing information for assuring the quality of service to consumers.

* Provision of accountability or summative reports for sponsors and consumers of the program.

* Enlightenment. This involves providing information which increases understanding of the experiences of participants in the program and the phenomena that are involved in providing the program (Stufflebeam and Shinkfield, 1985, p. 7).
Evaluations can play varying roles dependent on whether the evaluation is directed towards designing and implementing a new program or fine-tuning an established program. It is important to tailor the evaluation according to the needs of the program (Rossi and Freeman 1989, p. 113).

Dependent on the information which is valued, evaluations will have a focus on key informant groups such as managers, administrators and policy makers. Evaluations may serve a purpose in providing information for decision making processes or concentrate mainly on the day-to-day issues of program delivery to help people understand the functioning of their service activities and the degree to which services are respected and valued by clients. In order for evaluations to achieve the most useful results it is important that the method of obtaining information is congruent with the type of information required. Evaluation engages the evaluator in a political process with multiple stakeholders. It is important, therefore, that the evaluator clearly identifies the key stakeholders in the evaluation process and that the evaluation paradigm is carefully selected to address the needs of key stakeholders.

2.2. ALTERNATIVE PARADIGMS FOR PROGRAM EVALUATION

Traditionally, social science evaluation researchers employed scientific methods which relied on the logics of experimental design and statistical inferences in an attempt to explain causality within human service programs (Kagan, Kearsley and Zelazo, 1977; Kershaw and Fair, 1976; Rossi et al, 1989). However, measuring the success or failure of complex social, educational and health programs which are embedded in social and political life present complex methodological problems which confound hypothesis testing to verify theory. Ethical issues are also raised in the utilisation of experimental
designs which deny program participation to consumers for the purpose of comparison. Quantitative methods in social research require the development of measures which reduce complex phenomena to simple quantitative indices. Although this approach may be viewed as objective and meaningful from the evaluator's perspective, often the results are not meaningful to consumers, providers, funders and competitors.

The perceived shortcomings of the epistemological assumptions of logical positivism, therefore, have resulted in a shift from the scientific paradigm to a naturalistic approach in the evaluation of human service programs. The contextual relevance and powerful human-as-instrument approach inherent in naturalistic (or qualitative) inquiry, according to Guba and Lincoln (1983), provides more than adequate compensation for the 'objectivity' of rationalistic inquiry. The emphasis on a qualitative approach is to generate findings which are useful. Because human service programs are very complex phenomena, it is necessary to implement qualitative methods to examine program processes, operations, and descriptive outcomes, as well as quantitative methods to measure the 'measurable' parts of the program (Weiss, 1972, p. 43).

Programs frequently have unanticipated positive or negative consequences. Measurements of programs which are constrained by goal statements are unable to detect these effects. It is for this reason that Scriven (1972), has recommended 'goal free' evaluation as a fair method of determining truth in program evaluation. In agreement with Scriven's proposal Stake (1975, p. 14), also promoted a model of 'responsive' evaluation which he mooted as "... orienting more directly to program activities than program intents; responding to audience requirements for information; and reporting on the different value perspectives present." According to Stake, program evaluation is a
continuous and interactive process, the purpose of which should be "...determined by the purposes and information need of audiences" (Stake 1975, p. 14).

A number of extant models of evaluation have evolved from Stake's proposal and these can be described as 'pluralistic' in that they take into account the different value positions of stakeholders in the evaluation milieu and are therefore sensitive to the different values of program participants (e.g. Parlett and Hamilton, 1972; Patton, 1975). Alternatively, advocates of the scientific paradigm (e.g. Cook and Campbell, 1979) insist that rigorous methods such as randomised experiments or at least strong quasi experiments should be used to assess program effectiveness, believing that qualitative methods may provide misleading information which confuses decision making. In agreement with this perspective, researchers who favour critical methods (e.g. Cohen and Manion, 1989) maintain that research can legitimately look beyond the perceptions which individuals have to the ideological factors which influence their perceptions. In their criticism of the ability of social researchers to truly define a situation they argue that interpretative approaches may reveal misconceptions and confusion while leaving situations unchanged. The phenomenon of 'false consciousness' (i.e. acceptance of someone else's definition of a situation without criticism) is considered by advocates of critical methods to be a major problem in naturalistic research.

The basis by which a particular paradigm is chosen becomes obvious in the researcher's preference for a particular approach by their emphasis on validity as opposed to reliability or vice versa. Validity in quantitative evaluations depends on carefully constructed instrumentation to be sure that the instrument measures what it is meant to measure. Prescribed procedures are adopted to administer the instrument in a standardised manner. The benefits of this form of inquiry are that it is possible to measure the reaction of a great
many people to a program and scientific controls allow findings to be generalised. A disadvantage of this method is that a limited number of questions can be posed and the constraints of standardised procedures 'distance' the researcher from the informants. Qualitative evaluation methods produce thick descriptions of programs obtained from a much smaller number of people. This increases understanding about what is happening within a program but decreases generalisability. The role of the researcher is one of 'participant' who interacts with the informants and data directly.

Patton (1990, p. 14), suggests that both qualitative and quantitative evaluation methods involve differing strengths and weaknesses. Values are the fundamental basis for evaluation judgements according to Guba et al (1983). The choice of the problem, the way it is defined and the methodology instituted are dependent on the individual value perspectives of the evaluator who, either consciously or unconsciously, selects methods to explain human phenomena. A utilitarian approach to evaluation will promote a quantitative approach which is goal directed and has measurable outcomes. A deontological approach to understanding the experiences of participants in human service programs will value the information revealed by individual program participants in their own language and consider this of higher value in the assessment of program efficacy than quantitative measures of program outputs. Scriven's (1972) proposed idea of goal free evaluation advocated that this method allowed the evaluator to suspend judgement on what the program is trying to do and to focus instead on finding out what is actually happening within a program. The evaluator can then be open to whatever data arises from the program itself.

In opposition to this approach Rossi (1972) cited in Rossi and Williams (1972), proposed that evaluations can only be framed in relation to the formal stated goals of programs. Goal directed evaluations, however, only present information on pre-determined routine
components of programs making them fixed and stable. There is an inherent danger that
this approach could allow programs to become unquestioned and habitualised. By
accepting the general conceptions of what is done within a program evaluators may in fact
perpetuate situations which do not fully meet the needs of participants.

Program evaluations are generally undertaken to meet the accountability of funding
groups. A commonly used design within social science is a survey design using
consumer questionnaires to measure consumer satisfaction with service processes and
outcomes. This is a relatively simple procedure which generates systematic data on
people's perceptions of the effects of a program. This strategy, it may be argued, meets
the demands of funding bodies and supports political interests by demonstrating the
ability of government funded programs to demonstrate that the perceived needs of
participants are met. Apart from the phenomenon of social desirability response, the
vulnerability of program recipients and their dependence on program survival, lends this
method to manipulation and may in some instances misrepresent or exclude the
fundamental issues on which information is sought. The assumption underlying
satisfaction questionnaires is that they reliably and validly measure satisfaction. However,
as Gutek (1971, p. 48) remarked "... one reason for distrusting measures of satisfaction
is simply that people seem to be satisfied with everything social scientists ask them
about." Irrespective of this point of view, consumer questionnaires are frequently used
by evaluators to determine consumer perspectives of services received.

'Program Analysis of Service Systems Implementation of Normalisation Goals'
(Wolfensberger and Thomas, 1983), is an ideologically based evaluation which provides
objective quantifiable measures of service quality in terms of a program's adherence to the
principles of normalisation. Although valuable in terms of identifying concerns and issues
related to the coherence and quality of services, the underlying assumptions that coherent service models will result in positive experiences for individual participants, is questionable. Rich information from participants' perspectives on how the service is actually experienced by them is not provided. There is also a risk that program evaluation can become a series of research steps which are uniformly applied to various programs without concern for the theoretical implications of content, settings and participants (Chen and Rossi, 1987).

Dissatisfaction with atheoretical approaches which largely result in input/output or black box evaluations, focussing on the inputs and outputs of a program and ignoring the underlying causal mechanisms which generate treatment effects, has been expressed by Lipsey, (1987); Bickman, (1987) and Chen et al (1983). In their promotion of a theoretical approach to evaluation practice, Chen et al suggested that evaluators construct a theory of program processes and outcomes when implementing evaluation. This approach is also constrained, however, by the judgement of the evaluator related to what represents the causal effects of the program.

With the growing awareness of the problems faced in evaluation research methods, many evaluators (eg. Guba et al, 1985; Neenan, 1987; Bryman, 1988; and Denzin, 1989), advocate the use of a combination of methodologies so that the shortcomings of a single research methodology can be overcome. This also presents difficulties for researchers who have an affinity with either qualitative or quantitative methods according to their individual value perspectives. Time constraints, financial constraints and coherence in the evaluation design may also prohibit the use of multi-methods. In striving to understand the phenomenon or program as a whole Patton (1990, p. 53), suggested that a "...qualitative-naturalistic-formative approach is especially appropriate for developing
innovative programs or changing programs where the focus is on program improvement."

An evaluation which eliminates bias and maintains evaluator objectivity while designed to focus on the actual experiences of participants in relation to their interactions with the program will prevent the risk of a narrow study of program objectives and the possibility of missing the essential components of a program.

The selection of a coherent model of program evaluation presents an evaluator with numerous conceptual and methodological challenges. As the concept of value is at the heart of program evaluation, and there are a number of possible values that may take priority dependent on the evaluation focus, it is important that the method of obtaining information explicates the value frame on which the evaluation is based. Although evaluation "cannot resolve fundamental differences in the values of key players, it can help clarify just what these differences are" (Kirkhart and Ruffolo, 1993, p. 56).

When evaluation research is undertaken to identify program processes which are valued by participants, it is important to consider the different needs of participants related to their involvement with the program. When consumers and providers of services are involved, there is a risk that one methodological approach will satisfy one group but not the other. It is important to keep both consumer and provider groups represented within an evaluation so that the information obtained can be responsive to both groups and address their concerns in relation to the way the program operates.
2.3. THE UTILITY OF EVALUATIONS

The key to successful evaluations is that they must be designed to be used. As well as giving administrators a solid base for decision making and increasing a services' credibility, evaluations can give workers important information to increase their effectiveness and enhance their professional growth. In advocating the usefulness of services self-evaluating their programs, Austen (1982), discussed the importance of explicating the implicit assumptions held by staff within an organisation about the way services are organised to meet the needs of consumers. According to Austen (1982, p. 15), raising questions about these beliefs is an important ingredient in service evaluation and a critical factor in preventing evaluations becoming more than a "...self-servicing process to maintain the status quo." A higher utilisation of internal evaluations is also reported in studies by van der Val and Bolas (1981) (cited in Patton 1986, p. 451), who suggest that the success of internal evaluation is partly due to the higher rate of communication between inside researchers and policy makers. According to Attkisson and Hargreaves (1979) the systematic collection of data about a program when evaluation is built into a service allows reasonable judgements to be made about program effort, relevance, efficiency and effectiveness based on the regular gathering and analysing of information. Unlike laboratory research, however, which has long contended that it is value free, evaluation research acknowledges that its activities are laden with and influenced by societal judgements, pressures and priorities. The conflicting interests of evaluators, funders, workers and consumers of services may be further complicated when evaluators have an ongoing economic interest in a program. As it is unlikely that the values of all stakeholders within a program are fully congruent, an assumption can be made that internal evaluations may have an increased risk of bias both in methodology and reporting on findings.
Although any evaluation situation cannot be free of the influences of the individual value perspective of the evaluator, an external evaluation can offer a more objective examination of a program which is uncontaminated by organisation loyalty and other factors. Being external to the program and evaluator may be able to provide unique insights into the process. According to Nisbet (1974) cited in Tanji (1993, p. 149), the evaluator has the advantage of emotional distance which enhances consideration of negative evidence. This is particularly important in evaluation situations which are designed to critically view the processes of a program to assist program stakeholders towards a deeper understanding of what is happening within a program.

The need to evaluate, defend and improve programs is a concern for program administrators who need to continuously justify budget requests and maximise effectiveness of resource allocations. Estimating the economic value of a program's outputs and relating this to the costs of achieving the output has more power in a capitalist society if the program recipient is potentially an economically productive member of the community. Different values are addressed, however, when providing program opportunities for members of society who do not have a tangible economically productive future. Programs which focus on subjective 'quality of life' outcomes such as recovery from bereavement do not lend themselves to economic measures. Evaluation in this situation may be more relevant if focussed on the value consumers allocate to the program rather than meeting the accountability measures of external funding bodies.
2.4. THE ROLE OF RECOMMENDATIONS

When the purpose of an evaluation is to make improvements in a program, generating recommendations is a natural way to go about doing this. It is generally an expectation of administrators that recommendations are included in evaluation reports. Patton (1986, p. 268), suggests that "Recommendations are often the most visible part of an evaluation report. Well-written, carefully derived recommendations and conclusions can be the catalyst that brings all the other elements in an evaluation process together into meaningful whole."

In believing, however, that the status of formal recommendations is different within naturalistic evaluations Ryan (1993, p. 144), discusses the views of House (1979) and Kelly (1980), who use the term 'persuasion' to describe what they feel is a more realistic goal of program evaluation. This would appear more congruent with the role of the evaluator in naturalistic inquiry and the collaborative model adopted within this paradigm. Recommendations, therefore, are more in keeping with the expert-client relationship which is more characteristic of scientific research and in which the expert is advising the client to adopt a particular course of action. Within naturalistic evaluation, the evaluator's interpretative description of the program is more of an expansion and formalisation of their own insights rather than a radical revelation. The power of the report to persuade program decision makers "... resides not so much in the art of the evaluator to construct persuasive arguments; rather, it draws its legitimacy from having been arrived at through a process that is mutual and dialectical" (Ryan, 1993, p.145).

There is no place for the reductionist concept of recommendation in this view of program evaluation reporting. Presenting a description of the evaluation findings and arriving at a
shared meaning of what is valued within a program will in itself provide the necessary information for future program development.

2.5. CONCLUSION - PROGRAM EVALUATION

Program evaluation affects a range of stakeholders within human services with varying and sometimes conflicting needs and perspectives. It is important that evaluators are able to determine the perspective from which a particular evaluation should be conducted and ensure that this is clearly understood by program stakeholders and participants in the evaluation process. Because the value of an evaluation depends upon the way it is utilised by others, it is also important for evaluators to understand the context of the evaluation arena. In selecting a method of evaluation, evaluators are faced with the issue of the enduring paradigmatic debate between quantitative and qualitative methods. Although the two approaches to obtaining valid information are suitable for different and complementary purposes, the preference for a particular paradigm will be dependent on both the evaluation purpose and the values inherent in the value frame of the evaluator and what constitutes 'truth' from the evaluator's perspective. The values inherent in the selection of the method of evaluation will also affect the way in which the findings are reported and whether recommendations are stated per se or inferred in the description of what is valued by participants.

In order to evaluate the experiences of participants in a program, such as the one proposed in this study, it is necessary to develop an understanding of the reasons for their participation in the program. This has contextual relevance and will prepare the evaluator for implementing the investigation. Investigation of the philosophies underpinning hospice services and raising consciousness about the state of bereavement will increase
the evaluator's sensitivity to the needs of participants. This is particularly important in evaluating a bereavement program, as the means of collecting information from participants by a process of in-depth face-to-face interviews has many ethical implications and requires a particularly empathetic approach in order that participants are not distressed by the process.

2.6. INTRODUCTION TO BEREAVEMENT

Bereavement, grief and mourning are terms used in relation to surviving the death of a significant other person, often a close family member. Bereavement is a state involving loss and is the status conferred upon someone who has experienced a loss; grief refers to the feelings of sorrow, anger, guilt and confusion which arise when a person has suffered a loss; mourning is the overt expression of grief and bereavement (Kalish, 1985 p. 182). Grief is recognised as a necessary, normal and universal response, as a time for healing, adaptation and growth. Bereavement is complex, for it touches on what it means to be human and to have a relationship. According to Parkes (1972, p. 5) "The pain of grief is just as much a part of life as the joy of love; it is, perhaps, the price we pay for love, the cost of commitment."

Various societies exhibit a wide range of beliefs which have grown up around death and bereavement, often involving rituals which give social support for the expression of some of the emotions which arise following a loss. Within Western cultures there is tendency to divert bereaved people from the expression of their emotions, and societal pressures may inhibit the expression of grief in the early stages of bereavement. The privatisation of bereavement is consistent with other related cultural practices. Dissipation of the cohesive social bonding which previously may have helped people cope with grief is a feature of
the secularisation and mobility of current Western societies. A large body of literature supports the concept that grieving for a loss is necessary for effective functioning (e.g. Kubler-Ross, 1975; Bugen, 1977; Worden, 1983; Parkes, 1972, 1986).

2.7. THE COURSE OF GRIEF

Bereavement studies indicate that most areas of life are disrupted by the grieving process (Lund, 1989). Most authors describe an uncomplicated grief syndrome which has a more or less predictable course and distinctive symptoms. These are described by Martocchio (1985, p. 238) as "... a period of shock and somatic stress; feelings of guilt; hostility; interruption with life's usual activities; pre-occupation with thoughts of the deceased; and finally working through to a state of reintegration."

In outlining four tasks which need to be accomplished in order to move beyond grief, Worden (1983), suggests that first, the grieving person must accept the reality of the loss and that, in fact, the death has actually occurred. Denial of the death can lead to prolonged, unhealthy or even pathological grief. Abnormal grief can result in altered relationships with family and friends, feelings of generalised anxiety, depression and anger. This may make interactions with others very difficult. Secondly, according to Worden, the grieving person must accept that grief is painful. Unhealthy practices to divert the grieving person from experiencing pain (such as the use of drugs and alcohol), merely delay the grieving process and have contra-indications for health status. The third and fourth tasks of grieving involve withdrawing from emotional investment in the deceased and adjusting to an environment which no longer includes the person who has died. This does not mean forgetting the dead person, but involves being able to reinvest emotional energy in developing new and healthy relationships.
adjust and reorganise their lives. A significantly higher incidence of depression among bereaved widowers and widows compared with non-bereaved control groups was reported in studies by Glick, Weiss and Parkes (1974), Maddison et al (1968), and Parkes et al (1983), who concluded that physical health problems with an autonomic nervous-system basis, implying emotional origins, were also more likely to be reported by this group.

Other studies on the impact of bereavement on physical and psychological morbidity concluded that bereaved people are representative of a population which has an increased risk of physical, psychological and social dysfunction in comparison with the general population (Parkes and Brown, 1972; Helsing and Szklo, 1981; Stroebe and Stroebe, 1983; and Clayton, 1979). Particularly traumatic circumstances surrounding the death and a concurrent life crisis are factors which were identified by Raphael (1980) as precipitative of a difficult bereavement. Parkes (1981) and Sheldon, Cochrane, Vachon, Lyaly, Rogers and Freeman (1981) also identified predictors of the need for bereavement intervention related to the nature of the death, predisposing personality of the deceased, other life crisis and socio-economic status. Although many variables both in methodology and pre-bereavement health status of the populations involved must be considered before evidence can be accepted as conclusive, there is general agreement that mortality rates following bereavement are increased in bereaved populations.

2.9. BEREAVEMENT PROGRAMS

Traditional supports and ceremonies for the healthy expression of grief, including family and religious networks, are no longer practised by many people in our society (Dayle, Hanks and MacDonald, 1993). After a short period of open family and community
support the bereaved are often left on their own and expected to continue their lives without any outward signs of mourning. People may avoid the bereaved after the initial socially acceptable support period and at a time when support is most needed, bereaved people may find themselves alone and socially isolated. It is at this time that the risks of unhealthy dependence on drugs and alcohol is heightened. Unresolved feelings which need to be expressed in the early stages of grief may be inhibited at this time and cause maladjustment in bereavement which may affect bereaved people for many years or even for the rest of their lives and interfere with future life roles if an opportunity for resolution is not available.

Studies comparing individual responses to bereavement have identified variables which impact on the resolution of bereavement. These include, life crisis prior to bereavement; earlier experiences of loss; previous mental illness; relationship with the deceased; mode of death; personality; socio-economic status; nationality; religion; availability of social supports and future life options (Parkes et al, 1972). Irrespective of the individual differences in people who have experience a loss, it is widely recognised that grief resulting from the loss of a significant other can be very intense and multi-faceted. It may even throw every aspect of life out of balance (Rognlie 1989, p. 39). Emotionally, grief may evoke strong feelings of anger, guilt, fear and sadness. Mentally grief can cause confusion and even fear for one's own sanity, and physically grief can be experienced as insomnia, exhaustion or nausea.

Increased social recognition of the issues of death and dying has resulted in a greater interest in grief and bereavement intervention. The theory that support to people during bereavement might reduce the risk of negative bereavement outcomes has been substantiated in studies by Gerber, Rusalem, Hannon, Battin and Arkin (1975), Raphael
(1980), Parkes (1981), and Glasser and Glasser (1970). A positive relationship has also been established between bereavement support and recovery from bereavement by Longman, Lindstrom and Clark (1989), Byrd and Taylor (1989), and Lattanzi-Licht (1989). Knowledge of what to expect during bereavement can be very useful in helping alleviate people's fears about their own unusual feelings and behaviour during grief. The opportunity to talk and reflect on the life and death of the deceased can assist the person who is bereaved to accept that the death is real and in coming to terms with unresolved issues or feelings involving the deceased. This can help with working through and resolving grief and combats the negative health consequences of bereavement (Parkes, 1981; Rees, 1984; Tolle and Hickman, 1988).

2.10. PREVIOUS EVALUATIONS OF BEREAVEMENT PROGRAMS

Extensive literature is available to augment understanding of the nature of bereavement, the relationship between key variables in the grieving process, the identification of pathological grief reactions and the course of recovery, however, there is limited literature available on the evaluation of bereavement programs. Although the limited number of evaluations of bereavement programs have contributed to the body of knowledge in relation to the organisation of bereavement support within hospice services and the impact of bereavement support on bereaved populations, significantly, the methodology used reflected the need for accountability to funders of programs and either consumers or providers of programs were target participants. Investigation of bereavement literature has failed to unearth evaluations which have provided information on experiences of consumers and providers of bereavement programs and their perceptions of the program's value. A literature search has uncovered the following evaluations of bereavement programs.
A comprehensive study in London (Parkes, 1981), involved the development of a questionnaire based on eight predictive factors of poor bereavement outcome identified by Caplan (1964), in a longitudinal study of widows and widowers in Boston. Having identified people who were at 'high risk' of poor bereavement outcomes, Parkes then undertook an experimental study using people from the 'high risk' group and randomly assigning them to control and experimental groups. The experimental group was provided with bereavement support services. On follow up of one hundred and eighty one participants after twenty months of bereavement, Parkes demonstrated a significant association between 'high risk' and poor outcomes in the control group. Consumption of drugs, alcohol and tobacco, and the reporting of anxiety symptoms were reduced in the experimental group who also had utilised health services to a significantly lesser extent than the control group. Alternatively, a study to test the efficacy of three specific hospice objectives including impact of bereavement programs on bereavement outcomes of family caregivers was undertaken in Utah County by de St. Aubin et al (1986), using a quasi experimental design. Analysis indicated that there were no significant differences in any of the indicators of grief resolution and bereavement adjustments between the treatment and control groups. Design limitations of this study, however, related to the small size of the sample, (n = 28), and the use of a non-standardised rating scale and self-selection bias which interfered with internal and external validity.

In New York, Sabatini (1988), also undertook an experimental study to evaluate the efficacy of bereavement support group programs. A pretest and posttest design using the Texas Revised Inventory of Grief, was undertaken on an experimental group who received bereavement support, and a matched control group. Twenty-five people were allocated to each group and the study concluded that there was no significant difference on posttest groups. Recovery from grief was significantly influenced, according to this
study, by factors such as circumstances of death and time. However, due to the small numbers and homogenous characteristics of the sample participants in relation to ethnicity, gender and socio-economic status, a much larger population would need to be involved to validate results.

Longman et al (1989), in Tuscon, Arizona, interviewed ninety-seven people who had received bereavement support at thirteen months of bereavement. A Bereavement Survey Questionnaire consisting of seventy-one items including descriptive and open-ended questions to collect ordinal and qualitative data was posted to participants. Content validity was established by hospice team member review. Analysis of questionnaire data indicated that bereavement support was viewed positively by participants as assisting with grief resolution. Limitations of this study were the absence of independent validation of the survey tool and the possible response bias of participants who were willing to complete a lengthy questionnaire. Information from this study did, however, provide useful indicators for program reorganisation and development.

A similar study by Byrd et al (1989), in Oklahoma, to evaluate a hospice program from the perspectives of participants, involved the development of an evaluation tool using twenty close-ended questions including questions on bereavement support. A four-point Likert scale was used to measure each statement. A random survey of one hundred and two caregivers was undertaken. Analysis indicated that bereavement support was an area of concern to caregivers and that bereavement intervention was an important area of unmet need. Although this survey provided information on program strengths and weaknesses from the perceptions of this group of participants in relation to National Hospice Organisation Standards in America, it was limited in design and content. Likert
measures provide simple ordinal statistics which lack the accuracy of more rigorous statistical analysis and the thick descriptions which are obtained from qualitative studies.

In Winnipeg a longitudinal randomised study using two control groups and one experimental group undertaken by Scruby and Sloan (1989), aimed to evaluate the effectiveness of bereavement counselling as a health promotion strategy. Using the Lindemann (1944) model of grief management, thirty bereaved people were assigned to three groups, and tested on the Heimler Scale of Social Functioning (Heimler, 1975) at six points until eighteen months of bereavement. The study concluded that there was no statistical significance between control and experimental groups at eighteen months of bereavement in relation to their adjustment. The study, did, however, conclude that bereaved people are a population at risk of health problems. Methodological questions, however, must be asked in relation to the study design and the use of a measurement tool which utilises Likert type responses.

Perhaps the most comprehensive study of hospice services has been undertaken in the United States of America by Lattanzi-Licht (1989) to collect data on the form and functions of hospice service in America. A Bereavement Services Survey to four hundred and thirty nine provider members of the American National Hospice Organisation (respondents n = 253), provided comprehensive descriptive information on staffing of American hospice services and the scope of services provided as well as the strengths and weaknesses of programs and the need for further research. The study concluded that bereavement programs were an area which required research and development within the hospice movement. A lack of funding directed towards training and support for staff involved in bereavement was also identified.
In Western Australia a study of hospice services by Pestell (1991), used a postal multi-item questionnaire to retrospectively investigate caregivers perceptions of services delivered by all organisations involved in the care of terminally ill people in this state. A large number of respondents (n = 411), provided quantitative data on all aspects of service delivery including consumers' satisfaction with bereavement support programs. Valuable information on participant satisfaction with existing service components was revealed, however, rich descriptive data on participants experiences with bereavement programs was not provided. Providers of services were not included in this study.

The literature has demonstrated that evaluations of bereavement programs have focussed on the collection of quantitative data to measure service impact and satisfaction with services from consumers' perspectives. Literature on the effectiveness of bereavement programs is favourable but not conclusive. The purpose of this study is not to add to the literature on efficacy or satisfaction with bereavement programs. The fact that the hospice philosophy embraces the need to address caregivers' grief is a fundamental value of hospice services which forms the basis of bereavement intervention. This study will examine the experiences of participants in a bereavement program so that their involvement may be better understood by people involved in administering and funding services.

**CONCLUSION - BEREAVEMENT**

Bereavement is common to all people and will affect individuals differently depending on their relationship with the deceased, the circumstances surrounding the death, the individual's psychosocial and health status and pre-morbid personality. People adapt differently to grief and loss, however, there is much evidence to suggest that bereavement
is a critical event and one of life's major stressors. People who have survived the loss of a significant other have a higher risk of physical, emotional and psychological symptoms which interfere with their abilities to resume valued life activities. Although social support networks may provide significant support for people who are grieving, there is also a risk that negative network pressures and cultural mores will inhibit the expression of grief and disallow important grief work to be undertaken. The risk of unhealthy grief behaviours and the development of pathological grief reactions will then be increased.

As a result of extensive research in the area of grief and loss, there has been a heightened awareness of the needs of bereaved people, particularly those who are socially and culturally isolated. The development of services to address this need has been a consequence of empirical research. A number of studies have been undertaken to validate the provision of bereavement services, however, these studies have provided inconclusive evidence on the efficacy of programs related to resolution of grief. There are, however, other values to be considered in the provision of bereavement support programs. Human needs cannot always be measured scientifically. It is an acknowledged fact that people who are bereaved benefit from support to facilitate their journey towards recovery. An increasing number of people access professional assistance to support them in the resolution of their grief. These support services are provided by private practitioners or staff involved in hospice services.
CHAPTER 3 THE STUDY CONTEXT

3.1 AN INTRODUCTION TO HOSPICE SERVICES

The hospice approach to providing care for terminally ill people recognises the distinctive circumstances and needs of every individual facing death. Respecting the social integrity and supporting the interpersonal relationships of the dying person and their family is characteristic of this philosophy of care. A model of palliative care which is directed towards alleviating symptoms rather than curative strategies represents a departure from invasive medical procedures and allows families legitimate rights in the terminal care situation which is directed towards quality of life while dying. Hospice services also challenge the traditional domination of the medical profession by introducing an egalitarian approach into health care.

A number of social forces influenced the growth of the hospice movement in Western societies in the 1970's. A move towards consumerism in human service delivery in the United States in the 1970's saw hospice care as an innovative service which was worthy of advocacy (Mor, Greer and Kastenbaum, 1989). In replacing medical technology and impersonal management with intimate care, the hospice movement was also representative of a move towards 'naturalism' in which family values and community involvement in care were emphasised. Treating the whole person was also viewed as an approach worthy of cultivation, around this time. The 'holistic' approach provided by hospice and the involvement of patient, family, volunteer and professional caregiver in a unified approach to meet the need of the dying person and the needs of the caregiver to be supported during their grief, was preferable to the fragmentation so often evident in
medical services. Evidence that hospice programs could work was demonstrated most effectively by St. Christopher's Hospice, London by Dame Cicely Saunders who laid down a number of principles for the planning and development of a hospice service (Saunders, Summers and Telfer, 1981).

The underpinning philosophies which guide the delivery of hospice services affirm the rights of the patient and family to receive care within the parameters of their lifestyle. The patient has the right to maintain maximum control over his/her care which is planned according to individual needs. Care is provided by an interdisciplinary team to meet the physical, psychological, social and spiritual needs of the patient and is available twenty-four hours a day seven days a week. Care during the bereavement period is provided to the primary care giver or family to facilitate physical, emotional and social adjustment:

The hospice seeks to provide care for the terminally ill and is an alternative model to other health care institutions whose priorities are either with solely curing diseases (as in hospitals) or imposing custodial care (as in nursing homes) - both an affront to human dignity.

(Davison cited in Frey, 1980, p. 36).

Hospice care can either be provided in institutional or community settings. Although the emphasis on the home as the focus of a person's life is one of the features of the palliative care movement, there are situations which demand the facilities of an institution usually for caregiver respite or when there is no caregiver available. Services in Western Australia are both institutional and home-based. The focus of this study is the evaluation of a bereavement program in a home-based hospice service provided by Silver Chain Nursing Association.
Silver Chain Nursing Association is one of three providers of hospice services for terminally-ill people in Western Australia. Other hospice services are provided by The Cottage Hospice, a twenty-eight bed facility in Shenton Park, and The Palliative Care Unit at Hollywood Hospital which has twenty-two beds dedicated to hospice patients. A history of the growth and development of hospice services in Western Australia (Oliver, 1992), comprehensively describes the inception and growth of domiciliary hospice services. Initially funded as a pilot project for a period of six months in 1982, and jointly administered by the Cancer Council of Western Australia and Silver Chain Nursing Association, the home-care hospice service, due to increasing demand for hospice services, has grown to become the largest organisation providing services to families of people who are terminally ill in Western Australia. The service is now solely administered by Silver Chain and funded through the Home and Community Care Program with the assistance of public donations and bequests. The service had an operational budget of 5.2 million dollars in the 1992/93 financial year. There are no funds specifically dedicated to bereavement support services. Although the provision of such services is deeply embedded in the organisation's philosophy of care, funding bodies do not currently recognise the need to provide formal bereavement support for caregivers.

Silver Chain Hospice Care Service provides clinical, emotional and spiritual support to families in eight distinct metropolitan areas in a fifty kilometre radius of Perth by district teams. Families have access to physicians, nurses, volunteers, chaplains and a psychologist. Hospice services are provided to families without charge. Doctors are reimbursed through Medicare and other services are funded through Home and
Community Care funding. Within the period July 1992-June 1993, nine hundred and eighty-seven people in Western Australia accessed hospice home care services to assist with the care of their terminally ill family member. Each family has access to bereavement follow-up services.

Bereavement programs are an essential component of hospice care. The Executive and Council of the Australian Association for Hospice and Palliative Care Inc. which is the umbrella body for Hospice and Palliative Care services in Australia, has recently published seven standards for hospice and palliative care provision (1994). It is anticipated that services will be accredited and evaluated in relation to this set of standards in future. Standard six of this document relates to the implementation of bereavement follow-up support services to family and friends of the deceased, the establishment of policies to guide the program and a means of identifying people at risk of poor bereavement outcomes.

3.3, SILVER CHAIN HOSPICE CARE SERVICE BEREAVEMENT PROGRAM

Bereavement support for the families who access hospice home care is an integral part of the care offered. This is seen as an extension to the support of the carer after the death of the client. A bereavement co-ordinator is responsible for co-ordinating bereavement follow-up at each metropolitan base.

In 1994 it is estimated that the Hospice Care Service will care for 1,450 terminally ill people.
Currently the service operates on a time frame for planned contact over a four month period following the death. This period can however, be extended in particular circumstances, at the discretion of the service provider.

The service statement outlines the following objectives:

* Provision of support at the level appropriate to each individual.
* Provision of support with both practical and emotional aspects of grieving.
* Encouragement to the bereaved to identify and use the support and resources of their family, friends and the community.
* Resources of staff and volunteers.

(Silver Chain Hospice Care Service Statement, 1993)

A short assessment guideline to identify people in the 'high risk' group of bereaved caregivers is used by people providing the service. Referrals are co-ordinated at a base level and written documentation is provided following the initial contact.

Bereavement support is provided mainly by nurses and volunteers, with the availability of chaplaincy and counselling services if required. The recruitment and training of volunteers is an ongoing process. An in-depth orientation is provided to volunteer recruits by the volunteer co-ordinator, psychologist and other staff. Didactic and experiential learning situations are provided as an induction to working in the areas of loss and grief. Volunteers who are invited to work in a bereavement support role are carefully selected for this purpose. Ongoing workshops and training sessions are provided for staff working in the bereavement area. A library resource at the central base is accessible to staff and families and an information package explaining the purpose of
the service and the availability other community support groups has been compiled for caregivers.

In addition to individual bereavement contacts which may involve telephone contact or home visits, four bereavement support drop-in centres have been established in Bayswater, Duncraig, Hilton Park and Gosnells. Bereavement support groups have also been established in some metropolitan bases and a telephone 'grief-line' has been recently instituted to provide an opportunity to callers who need to talk about their feelings and grief experience. An invitation to an annual interdenominational service on St. Lukes Day is sent to all caregivers, who also receive a commemorative card on the first anniversary of the death of their family member.

As with any individually tailored service, the implementation and nature of bereavement support varies according to the needs of families and the skills of providers in analysing and meeting those needs. Service guidelines are not rigid and allow for flexibility in delivery. It is for this reason, that evaluation of a program such as this, using a formal approach involving surveys and questionnaires, may exclude the gleaning of information on the true meaning and utility of the program to participants. This information can only be obtained by prolonged interaction with participants and analysis of their experiences with the program. The lack of dedicated funding for bereavement support and the increasing resource demands of clinical services as the public demand for hospice home care services increases, indicates that bereavement support programs are at risk of reduced resources. It is timely, therefore, to develop a method of evaluation to explore the experiences of people who have been involved and who are currently involved with the program to ascertain what value the program has from their perspectives.
CHAPTER 4. THE CONCEPTUAL FRAMEWORK

The theoretical framework underpinning the study is symbolic interactionism. This theoretical perspective has its roots in sociology and has an assumption that society, reality and selves are socially created through interaction processes (Blumer, 1969; Lindesmith, Strauss, and Denzin 1975). Meanings (or truth), therefore, arise out of the individual's experience.

The symbolic interactionist position has the view that:

* Human beings act in situations on the basis of the meanings situations have for them.

* The meanings derived from situations arise out of social interaction between people over time.

* Meanings are handled through an interpretative process used by the person in dealing with the situation at hand (Blumer, 1969, p. 3).

Meaning is, therefore, related to the practical aspects of experience and meanings emerge as people interact. The adoption of a symbolic interactionist approach to the analysis of participants' experiences with a bereavement program postulates that services are constructed through continuous interaction over time. The interactionist position, as described by Charmaz (1980), is based on the view that interaction consists of an interpretative process. This stresses a view of human nature as being reflective, creative and active. Subsequently the human capacity for reflection is heavily emphasised.
In believing that the need to identify the consequences of human service programs for participants in terms of their experiences with services is integral to useful human service evaluation, this study will undertake a symbolic interactionist approach to evaluate a bereavement program, and will ask what it is like to experience the program from participants' perspectives. The meaning of the program will be dependent on the value and definition the program is given by participants in the context of their own lives.

The need to include both consumers and providers in the study promotes an interactionist view that reality is a social construction shaped by interpretations, choices and actions of participants (Charmaz, 1980). The existential nature of the human service environment is also acknowledged by including people who receive and deliver the service in the construction of the meaning of the service. The service environment is seen, therefore, as an interactive milieu in which consumers and providers interact with the service and with each other. In advocating a symbolic interactionist analysis of the findings of human service research Joffe (1979, p. 237), suggested that:

...the close examination implied by an interactionist analysis can not only lead to a deepened theoretical understanding of the service, but also on a more practical level might help to answer the perennial question of why some service programs 'work' and other do not.

As a result of the policies, interorganisational mechanisms and philosophical underpinnings of human services and the role they are perceived to play in the social order, lines of inquiry into human services have tended to focus on what services are 'for' rather than what they are 'like'. A focus on the actual program content which grasps the way services are experienced by participants has not been an important feature of these approaches.
Charmaz (1980), suggested that the need for any sociological exploration into the social reality of death must come to grips with values. This must also be applied to investigations into bereavement services. Whether values are fixed and stable within a service or are open to reinterpretation, they give rise to the construction of the reality of the service. Values not only give rise to the meaning of bereavement programs but also to the everyday practices through which bereavement is handled. As values shape and are shaped by experience, the types of experiences individuals have within a program will contribute to their view of the program. Internalising the values of a bereavement program and the service expectations in relation to recovery and adjustment, may work positively for some participants by providing concrete objectives to work towards. In other people, however, this may result in inhibition of the expression of needs by participants who require prolonged contact with the program but who feel obliged to conform to predetermined program expectations. As a result, individuals may be unable to fully utilise the support at hand and their needs may remain unmet.

Much of the research into bereavement programs has used methods which have consisted of imposing meanings of programs on people who are studied rather than eliciting meanings from them. The purpose of this study was to promote a framework for evaluation which acknowledged the ability of participants to give true accounts of their experiences according to their individual interpretations of events. An underlying assumption was, that it would be possible, through the analysis of participants' descriptions, to identify commonly valued interactions between consumers and providers of the program and influences on, and barriers to, these interactions occurring.
The conceptual framework for the study is represented in the following diagram:

![Diagram](image)

Figure 1.

The meanings of the interactions between program participants influences the consequences of program implementation and perceived value of the program to participants.
5.1. RESEARCH PARADIGM

The relative value of experimental methods versus naturalistic approaches in social science research has been the subject of long-standing debate (Blumer, 1980; Patton, 1990; Leininger, 1985). In promoting a symbolic interactionist approach to the study of social phenomena Blumer (1969), suggested that the human environment does not consist of objects which intrinsically carry meaning, but that social life is constructed through interaction with others (cited in Denzin, 1969, p.923). According to Blumer, variables cannot be detached from the context in which they operate without misunderstanding. Blumer also suggested that the use of survey methods to clearly define concepts in social research involved loss of meaning in the concepts they were intended to capture. Using statistical techniques in attempting to determine correlations among sociological variables to identify causal relationships, does not recognise the dynamic nature of the social research context. As the dynamic nature of bereavement programs result in changes and the redirection of programs over a period of time, an experimental approach to evaluate single episodes which compare a treatment group to a control group on a limited set of standard measures, would be meaningless.

A naturalistic mode of inquiry which takes into account the constructive character of human behaviour suggested that an open-ended investigation of the phenomena under study is preferred (Blumer 1980). In undertaking naturalistic research Leininger (1985, p. 5), suggested that the researcher should adopt methods of "... observing, documenting, analysing and interpreting, attributes, patterns, characteristics and meanings of specific, contextual or gestaltic features of the phenomena under study."
In agreement with this view, Guba et al. (1983, p. 235), proposed that naturalistic research offers a contextual richness and relevance unmatched by any other paradigm. By adopting an holistic approach to evaluation research, such as the one undertaken in this study, an understanding of the context of the service was essential to the overall understanding of the multiple aspects of the service. The human-as-instrument approach allowed for flexibility, insight and ability to build on tacit knowledge. This was particularly suitable in researching sensitive areas such as a bereavement program and promoted a humanistic viewpoint that evaluation methods should not depersonalise a significant human event. The mutual nature of the information flow was based on an assumption that participants knew, or were capable of knowing, the niceties of the program being evaluated. According to Ryan (1993) this allows the evaluator and participants to dialectically build an interpretation of the program under study. A naturalistic approach, therefore, allowed the researcher to value and understand naturally occurring phenomena without attempting to manipulate the context in which they occurred. This permitted interpretation of the world views, meanings and values of the program from participants' perspectives.

According to Patton (1990), qualitative inquiry is particularly relevant to process evaluation to discover how a program operates. A focus on process in evaluation research concentrates on how something happens rather than the outcome or results. A process evaluation can reveal areas in which relationships within services can be improved as well as highlighting the strengths of a program. In understanding the unique dynamics of a process, Patton (1990, p. 96) suggests, that it is helpful to approach the situation without predetermined hypothesis about what may exist. This was particularly relevant to capturing the experiences of people within a bereavement program and valued their abilities to define their interactions with the program.
An inductive analysis of transcribed, in-depth, open-ended interviews allowed the researcher to derive consensually validated knowledge on the qualitatively similar and different ways in which people experience, conceptualise and understand a bereavement program. Using grounded theory techniques for data generation and analysis (Glasser and Strauss, 1967; Strauss and Corbin, 1990; Powers and Knapp, 1990) the researcher could focus on role development and role relationships within the program from a symbolic interactionist point of view. Research outcomes enabled the researcher to gain an understanding of the way in which participants in a bereavement program interacted, shared experiences and created meanings which determined the value and usefulness of the service from their perspectives. As the purpose of the research was the description of what was valued within a bereavement program from the perspectives of program participants in relation to their experiences with the program, a phenomenological approach was implemented to generate this knowledge.

5.2. PHENOMENOLOGY

Phenomenological research has its roots in existential philosophy which focuses on the lived experience of people in their natural environment. Extensive literature is available to justify the use of this method in social research. (Benner, 1985; Knack, 1984; Munhall and Oiler, 1986; Omery, 1983; and Parse, Coyne and Smith, 1985). Phenomenology offered a way of viewing the human experience of a bereavement program. The descriptive nature of a phenomenological study provided a portrait of what it was like to participate in a bereavement program, revealing implications for the delivery of the service which could enhance its value to participants. The assumption in using a phenomenological approach was that "...there is an essence or essences to shared
experience and that these essences are mutually understood by people sharing a common experience" (Patton, 1990, p. 70).

The implementation of a phenomenological approach to evaluate a bereavement program permitted the uncovering of the shared meaning of the program by identifying the phenomena existing within the program from participants' experiences. The interactions between the participants and the program could then be more clearly understood.

According to Macquarie (cited in Kretlow, 1990, p. 8), phenomenology offers an in-depth description permitting features that would not normally be noticed to emerge from events, and allows a different view from the one revealed when a phenomenon is considered in isolation. The methodology of phenomenology allows the researcher to extract "... the essence, structure or form of both human experience and human behaviour through description" (Valle and King, 1978 p. 7). The content of the data, therefore, was dependent upon the description of the interactions which were considered salient by participants. Participants were encouraged to provide information according to their perspectives of what was important and valued. The intention of the use of a phenomenological approach in the evaluation of a bereavement program, was not to generate empirically based theory, but to provide an interpretative account of the experiences of participants as they were lived. In this way issues could be studied in depth and detail without the constraints and limitations of predetermined categories of analysis (Powers et al, 1990). Phenomenology differs from qualitative descriptive and ethnographic methods in that phenomena are studied from the participants' unstructured descriptions of lived experiences (Salsberry, 1989). Participants do not, therefore, answer prepared questions. An assumption underlying this method is that the reality of the phenomena under study, in this case a bereavement program, can be understood
through participants' meaning-giving descriptions. By allowing unconstrained descriptions of the lived experiences of participants, the researcher was able to obtain data which reflected their personal realities.

5.3. SAMPLE

In keeping with the conceptual framework, consumers and providers of the service were interviewed. Thirty bereaved carers, ten nurses and ten volunteers were involved in in-depth interviews with the researcher between July 1993 and December 1993. This group was representative of a cross section of consumers and providers of bereavement support. According to Patton (1990, p. 185) "The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information - richness of the cases selected and the observational/analytical capabilities of the researcher than the sample size."

The size of the group was considered large enough to achieve adequate variation and reflected the assumption that in-depth information from a representative population would provide valuable information regarding the consequences and usefulness of the service. Another consideration in determining the size of the sample was the necessity to provide current and useful information to the service to be considered in the future development of the program. The time and resource limitations of the researcher determined that a manageable amount of data was collected which would provide credible information for current use. The number of participants was not, however, prescriptive, and flexibility was incorporated to allow for further theoretical sampling for verification of relationships between categories if this was required. Both open and discriminate sampling techniques were used (Strauss et al, 1990). Discriminate sampling was used to select carers to verify
relationships and search for negative cases following analysis of the initial interview transcripts. Explanations of the sampling methods for each group of participants follows.

5.4. BEREAVED CARERS

This group consisted of thirty people. Twenty-three female and seven male bereaved carers between the ages of thirty-seven and seventy-eight years were interviewed between July and December 1993. Twenty-eight of the carers had lost spouses and three had lost parents. This group represented consumers of services who were currently involved with the service or had received the service in the past. It was considered appropriate to interview people who had disengaged from the service, to collect retrospective accounts of their experiences, as well as people currently involved. Although retrospective accounts of program experiences may have affected the accuracy of information collected, the fact that people receiving a service of this nature, were likely to be highly vulnerable and dependent on the service for support, may have resulted in response bias in the newly bereaved group of carers. It was also important in terms of reliability that multiple participants were sought. The process of disengagement from the service from carers' perspectives and possible areas of unmet need were significant areas to investigate and retrospective accounts of involvement with the service were the means of obtaining this information.

Investigation of the literature on the nature of bereavement consistently identified the first year of bereavement as a critical period in terms of recovery, mortality and morbidity (Glick et al, 1974; Worden, 1983; Stroebe et al, 1983 and Parkes et al, 1983). It was decided, therefore, to sample three groups of carers at different stages of grief. In order to avoid particularly sensitive periods, such as the anniversary of the death, interviews
were timed to span from four weeks to fourteen months following the death of a significant other. Three discrete groups of carers were identified and ten carers from each group were interviewed.

5.5. BEREAVED CARERS GROUP 1

The names of twenty bereaved carers who had been bereaved from between four weeks and four months were randomly numerically selected from service records. Although random sampling techniques are not characteristic of qualitative methods, it seemed appropriate due to the large numbers of people accessing the service and the absence of information which would indicate that any particular group of consumers should be the focus of the study, to obtain initial data by random means. Equal numbers of males and females from each of the eight metropolitan bases were selected. To ensure that carers would not be distressed by being contacted regarding the study, the names of the selected carers were made known to nurses who were providing support, so that carers could indicate whether or not they could be contacted. In some cases nurses did not consider it appropriate to approach carers due to the nature of their grief and these names were removed from the sample. Following nurses' informal invitation to carers and carers' agreement, a letter was sent by the service manager to selected carers formally inviting them to participate in the study. (Refer Appendix 2)

Four female and two male carers responded by completing an acceptance form and returning it to the central base in a stamped addressed envelope which was supplied by the researcher. Following this, the researcher contacted carers by telephone to arrange mutually convenient times for interviews which took place between July and September 1993. A further four carers were selected on the basis of verifying or negating story lines.
which had emerged from the analysis of the initial six interviews. These carers were approached in the same way. All carers in this group were interviewed in their homes. The researcher’s telephone number was made available so that arrangements could be changed, or carers could withdraw at any time. This group provided information on their current experiences with the program and their perceptions of needs met and unmet by the program.

The necessity of using nurses as gatekeepers who were able to prevent access to carers who may report negative aspects of the service is a limitation of this sampling method. Ethical considerations, however, overrode this factor due to the sensitivity of the research area and the importance of maintaining positive relationships between carers and the service.

5.6. BEREAVED CARERS GROUP 2

The names of sixteen bereaved carers who had been bereaved between six months and eight months and who were no longer receiving services, were randomly numerically selected from service records. All regional bases were covered and six men and ten women made up this sample. This gender distribution was representative of carers who had used the service during the period nominated. Letters were sent to this group from the service manager inviting them to be involved in the study and providing a stamped addressed envelope for their response. Seven carers responded, six female and one male, and they were contacted by the researcher to arrange interview times. A further three carers, one male and two female, were selected to verify or negate story lines which emerged from the analysis of the previous seven interviews. This group were interviewed between August and October 1993 and provided information on their
retrospective experiences with the program, the process of disengagement from the program and their perceptions of needs met and unmet by the program.

5.7. BEREAVED CARERS GROUP 3

The names of sixteen carers who had been bereaved between thirteen and fourteen months and who were no longer receiving services were randomly numerically selected from service records. All regional bases were covered and six men and ten women were selected. This gender distribution was representative of carers who had used the service during the period nominated. Ten carers responded, two men and eight women, who were interviewed between August and December 1993. At this stage, data analysis had reached a point of saturation and no further sampling was necessary. This group had survived the 'critical' first year of bereavement and provided information retrospectively on their experiences with the program, including contact made on the anniversary of the death, the process of disengagement and their perceptions of needs met and unmet by the program.

The lower sampling rate of male carers, and consequently fewer males being involved in the study is representative of the fact that numbers of female carers greatly outweighed males in service records. It was also considered important by the researcher to ensure that representatives of all bases were included due to the significance of evaluating a regionalised service. Furthermore, literature searches related to gender differences in bereavement response had provided insufficient evidence that gender issues related to bereavement would be an important consideration in undertaking this study (Stroebe et al, 1983 and Clayton, 1979).
5.8. NURSES

The names of ten hospice nurses, nine female and one male, between the ages of twenty-eight and forty-one years who provided bereavement support and who had been involved with the program between five years and eleven years, were randomly numerically selected from service records and sent a letter of invitation to participate in the study signed by the service manager. Care was taken to involve nurses from all metropolitan bases. Two nurses, one who had a liaison and co-ordination role at a public hospital and one who operated from the central base were also involved. All members of this group agreed to be interviewed. Two were interviewed at home, and eight at work sites between September and November 1993. This group provided information on service providers' experiences with the program, their perceptions of the value of the program to carers and the processes which determined positive and negative outcomes for carers and nurses from their perspectives.

5.9. VOLUNTEERS

The names of ten volunteers, between the ages of fifty-seven and seventy-one years who had been involved with bereavement support services for between three and eleven years were randomly, numerically selected from service records and sent letters of invitation to participate by the service manager. All volunteer participants were female as this was representative of this group. Care was taken to involve volunteers from all metropolitan bases. All members of this group responded positively and all were interviewed at home between September and December 1993. This group provided information on their experiences as volunteers in the program, their perceptions of the value of the program to
carers and the processes of the program which, in their perspectives, determined positive and negative outcomes for carers and volunteers.

5.10. DATA COLLECTION

In keeping with a phenomenological approach data collection involved a series of in-depth interviews. In-depth interviews involved face-to-face encounters between the researcher and informants directed towards understanding informants' perspectives on their experiences as expressed in their own words (Taylor and Bogdan 1984, p. 77). By retrieving the informants' world and attempting to understand their perspectives in language which was natural to them, the possible distorting effect of using symbols and language which were not part of their everyday usage was reduced. In-depth interviewing is particularly useful when a researcher wants to gain access to, and an understanding of, activities and events which cannot be observed directly by the researcher (Minichiello 1987).

In the context of a hospice home care bereavement program in-depth interviewing allowed informants who were currently, or who had previously participated in the program, to give accounts of actions and patterns of actions relevant to their involvement. By conducting interviews in the homes and places of work of informants according to their preferences, an informal and familiar environment was created which helped in the establishment of rapport.

The interview format consisted of asking informants to provide descriptions of events and experiences. This was considered a non-threatening strategy and allowed the informant to take control of the interview (Spradley, 1979; Taylor et al, 1984). Probing questions
were used to gain more detailed information and questions were asked only when the researcher found it necessary to clarify what the participant was relating. Participants' feelings regarding interactions which had been of particular significance were actively pursued. Initially the researcher had considered using a series of semi-structured open-ended questions in the interview situation, however, on piloting this format with one participant from each group, the interviewer decided that this method inhibited the information flow in a situation which proved to be an emotional experience for many carers. Structuring the interview questions also restricted nurses' and volunteers' responses by pre-determining areas of importance. A structured interview format was, therefore, deemed inappropriate in this situation.

Each interview began by the researcher asking the following question of participants:

* "Would you like to tell me about your involvement with Silver Chain Hospice Care Service?"

This allowed participants to tell as much of their stories related to their involvement with the service as they wished. In terms of bereaved carers, the important interactions with the service prior to the death and how this related to the bereavement support service was described. In terms of nurses and volunteers, valuable insights related to their decisions to join the service were revealed. The other question asked of all participants following their description of their involvement with the service, was:

* What is (was) bereavement support like for you?
Communication between the interviewer and participants then proceeded according to the direction participants' chose.

The recording of interviews was a means of obtaining a full and accurate record and validity was enhanced by the preservation of authentic data. Prior permission had been obtained from participants to record interviews. Interviews ranged in length from forty minutes to ninety minutes. This was exclusive of the time spent with informants initially to establish rapport and answer questions related to their involvement with the study and assure that confidentiality would be maintained. Field notes were not recorded during interviews as this may have inhibited participation in communication by the researcher. Field notes, related to the researchers observations and experiences of the research situation, were recorded following each interview.

Transcription of interview tapes generated approximately fifteen hundred pages of descriptive information related to informants' experiences with the service. The researcher travelled over two thousand four hundred kilometres in collecting the data from the eight operational areas of the service.

5.11. ETHICAL ISSUES

The qualitative exploration of sensitive topics may involve the living of intensely emotional experiences for participants, such as the group of carers in this study (Benoliel, 1975). Every effort was made to ensure that participant carers were not unduly stressed during the interview situation by conducting interviews in their home environments with a researcher who had counselling experience. The possible need for therapeutic intervention if this became apparent as a result of information disclosed, was discussed
with the service prior to undertaking the study to ensure that support would be available (Cowles, 1988). All research participants were assured that confidentiality would be maintained and participants were informed that they could withdraw at any time.

The value premises which underlie the general conduct of evaluation programs are defined as, honesty, fairness, sensitivity to program context and primary obligation to program participants (Connor, 1990). It was a necessary ethical outcome that this evaluation provided information which would be useful to the service and that the findings of the study would be available in a format which was comprehensible to the research participants. Approval was obtained from the Silver Chain Hospice Service Ethics Committee and Edith Cowan University Ethics Committee prior to the commencement of the study. Confidentiality in the handling of recordings was maintained by assigning a number and code to participants. No other records have been kept which identify participants by name. On completion of the study, tapes will be destroyed and transcripts are housed in a locked filing cabinet where they will remain for a period of five years according to NH and MRC requirements and then destroyed. In analysing the data and documenting results, the researcher will ensure that no documentation will be published which may prove harmful or embarrassing to participants or the organisation.

5.12. DATA ANALYSIS

Recorded interviews were transcribed verbatim. A grounded theory approach was adopted to analyse data (Glasser et al, 1967). Data was collected and analysed simultaneously by an analytical induction method which involved direct interaction
between the researcher and data over a period of time. The process outlined by Colaizzi (1978) was followed to analyse data:

* Review of the literature on evaluation, grief, loss, hospice services and bereavement programs prior to the collection of data.

* Collection of participants' descriptions of their experiences with the program through face-to-face, in-depth interviews. Keeping extensive field notes of the researcher's experiences. Field notes were reviewed during analysis of interview transcripts and added to the contextual richness of the analysis.

* Reading interview transcripts and listening to the tapes in order to acquire a feeling for them. Recording reflections and emerging clusters of codes and meanings and using a card index for storage.

* Extracting significant statements and highlighting text in transcripts. Statements were eliminated which contained the same or approximately the same statements.

* Categorising each significant statement and identifying its meaning. The meaning of persistent statements were spelled out.

* Clustering meanings and using codes to develop clusters of themes. This allowed for common themes to emerge which were consistently present in participants' descriptions. Clusters of themes were referred back to the original descriptions in order to validate them.
* Writing descriptions of the emerging phenomena including its essential structures and essences. Researching literature on bereavement, hospice nursing and volunteers to validate findings.

* Returning to participants and collecting further data to validate descriptions by incorporating this information into subsequent interviews. As each interview was analysed in order of implementation, new information which emerged from interviews could be incorporated in subsequent interviews as it arose.

* Testing propositions by seeking negative cases to validate assumptions. This was accomplished by a process of theoretical sampling. It was, therefore, important to involve participants whose needs had not been met by the service, and sampling continued until such cases were identified.

In this way data collection and analysis became more discriminate as emerging hypotheses were constantly being compared against the data until the point of saturation occurred.

Eight major themes emerged from the analysis of transcripts. These themes were connected to categories of interactions within the program which had consistently emerged from participants' descriptions. Influences on, and barriers to, the valued interactions described by participants were also consistently present in the data. These valued interactions were clustered as 'help activities' and their value to participants was described under each theme. Data analysis continued until the descriptions of valued activities, influences and barriers were exhausted. The most significant and consistently emerging themes and help activities for each group was then organised into a
diagrammatic format to include in the final report. It was then possible to identify elements of a valued bereavement support program and influences and barriers affecting valued activities from the perspective of the three groups of participants.

5.13. DATA TRIANGULATION

Triangulation in research has been defined as the combination of two or more theories, data sources, methods or investigators in the study of a single phenomenon (Denzin, 1989). In qualitative evaluation studies Patton (1990, p. 467), suggested that evaluators cross-check the consistency of information. Two of the methods proposed by Patton involved checking for the consistency of what people say about the same phenomenon over time and comparing the perspective of people from different points of view e.g. staff and client views. Both of these methods of triangulation have been used in this study. Triangulation provided strategies for reducing systematic bias in the data and allowed the researcher to defend against possible accusations that the study's findings were weakened by evaluation bias. As this study design involved a phenomenological approach which might have been viewed sceptically by supporters of more scientific methods, as a valid means of obtaining data for a program evaluation, the researcher implemented multiple strategies of triangulation to strengthen the reliability and credibility of the research findings.

The methods of triangulation instituted to test data reliability were:

* Multiple data sources presented diverse views about the program (Denzin, 1989). Information was obtained from three groups of people who had different roles
within the service (i.e. carers, nurses and volunteers) and fifty in-depth interviews were conducted over a five month period.

* Time triangulation by collection of data on the same program at different stages of grief during the first year of bereavement (Denzin, 1989).

* Collection of data from multiple sites (Miles and Hubermann, 1984). Information was obtained from eight metropolitan bases from which the service operated.

* Analysis of relevant literature and constant comparison with interview data as common categories and themes consistently emerged during analysis. This involved the investigation of new literature sources as themes were emerging.

* Peer triangulation by a colleague who had completed a doctoral study using grounded theory techniques. One interview transcript from each group of participants was coded by this colleague and then compared with the researcher's analysis. Ongoing peer review of data analysis by colleagues experienced in qualitative methods continued throughout the analysis period.

Member checking to enhance credibility was not undertaken for ethical reasons. The volume of data and the consistently emerging patterns from each group of participants, which were continually validated over time, in conjunction with other triangulation methods, provided sufficient credibility.
CHAPTER 6. FINDINGS AND DISCUSSION

The purpose of this chapter is to present the findings of the study and discuss the meanings of the findings by investigating relevant literature to support the discussion. Each major theme for each group of participants is described separately and validated by using direct quotations from the narratives of participants. A discussion of each theme follows the description. The way in which themes from the three groups are linked to form the interactive environment of the service, is then discussed.

* (Numbers and brackets after each quote from participant transcripts relate to sample group and coding system).

6.1. BEREAVED CARERS

THEME 1. MUTUALITY

(PARTNERSHIP FOR A PURPOSE)

Interviews with bereaved carers were dominated by their description of the relationships which had been established with nurses and volunteers prior to the death. This theme was consistently present in transcriptions from all groups of bereaved carers.

Mutuality refers to the person-to-person relationship and shared sense of purpose which develops in the care-giving environment. Mutuality in a service relationship means that the service provider brings herself/himself as a 'person' to the service environment and allows the consumer of a service to do the same. A reciprocal relationship between provider and consumer can then develop. Twenty-eight of the thirty bereaved carers used the words 'friends' or 'family' to describe the unique relationship which had
developed between nurses and carers. Two carers described this relationship with a husband and father respectively:

"Their visits are so appreciated because he was one of their 'friends'. They were so sincere about it. I couldn't have talked to a stranger, but I was able to talk to them. I couldn't have imagined that a stranger would have understood. They were just like 'family'." (1,2,14,14)

"I think that if it's someone that has been involved with the months leading up to that person's death, a special relationship has already been formed and that person then can offer, and will be allowed to offer, help. Whereas, I do feel that when another stranger presents themselves, as much as they are qualified and have been through grieving with other people, I think you automatically think twice about it. (2,3,24,8)

Mutuality continued throughout the bereavement period with the recognition from carers that nurses had also shared a loss. Narratives of bereaved carers described the sharing of grief with nurses who visited after the death and the mutually comforting nature of the relationship. This is revealed in the following statement by a carer who had received nursing support for six months prior to the death of her father:

"The relationship that I built up with those girls made me really realise that they grieved as well. That they really did understand, and that they had been through it with me."

(2,3,34,8)

Sharing memories of the deceased and the process of the illness and death with familiar nurses and volunteers allowed carers to express feelings related to their coping ability during the illness. This was particularly important when conflict situations had arisen.
between the ill person and carers resulting from stress in the pre-death period as well as some of the positive and sometimes humorous episodes which had arisen in the course of the illness. Frequent references were made by carers regarding mutual sharing of experiences of the deceased. This is described by two widows:

"The friendship and support that I felt and the relationship they built up with my husband carried me through...and the nurses shared the experience, and not only that, they shared their life and our life for that time. You can't separate before death and after death" (1,1,9,11)

"With (volunteer) coming, she gives me support. We can talk about (husband) and the work he used to do. He used to be a professional pianist and he, of course, talked to her about that and about the past." (1,7,6,5)

The reciprocal nature of her relationship with nurses providing bereavement support which was established during the pre-death period was demonstrated by a newly widowed carer:

"It was the relationship that built up before that was important and it was so good to see them afterwards. It wouldn't have been the same if a stranger had called in because it wasn't just asking me how I was going, but also I would ask them...'did you have a good trip, how is your family, how was the holiday?'" (1,1,9,12)

Valued help activities from carers' perspectives were, therefore, strongly linked to contact visits from nurses and volunteers who had been involved with the carer and deceased prior to the death. Mutuality was most likely to develop when the nurse or volunteer and carer had consistent lengthy contact prior to the death. The continuation of the mutual
relationship into the bereavement phase, was highly valued by carers and influenced their
view of what they determined was a positive bereavement service experience. The
shared experience between nurses/volunteers and carers of the deceased, and the process
of death, allowed carers to test reality that the death had actually occurred. Two widows
explained the unreality of their recent losses and the role nurses' and volunteers' visits
had played in helping them confront reality:

"Sometimes I feel as if I'm going mad. I wake up expecting to see him. I can't believe
he's gone. I know that if I need them (nurses) I've only got to ring. That's very
reassuring you know." (1,3,8,11)

"I think if they had not come afterwards, it might have almost felt as if it hadn't even
really happened in a way. You know, you shut it out. I think them (nurses) coming back
and me being able to realise that they had gone through it as well as me, gave me a feeling
of being able to share." (2,3,22,7)

A carer described how her perceived ability to cope was reinforced by continuation of the
partnership with a familiar nurse who had given her the strength to 'cope' with the
difficult caring tasks involved whilst her husband was alive:

"Definitely I feel that because of hospice I learned very much. I give credit to hospice,
not for getting over it, because I don't think I'll ever get over it, but they helped me
immediately, and as time went on their words kept coming back to me when I was feeling
down...their wisdom kept coming back to me and I put it down to them for getting on
with my life." (3,9,12,5)
Carers highly valued the availability of support which was reinforced by contact with nurses and volunteers whom they had come to trust in the past. Nurses’ and volunteers’ expertise as a result of their contact with many bereaved people was recognised by carers who felt confidence in their ability to ‘cope’ whilst nurses and volunteers provided support:

"I’m always happy to see them (nurses) because I need reassuring that everything’s going all right. They know the sorts of things I can expect to feel and to happen, because they’ve been through it with so many other people."(1,2,2,5)

It was also important for carers to have an opportunity to close their relationship with nurses and volunteers who had been involved prior to the death:

"They (nurses) were just like a family. They cared about you. I got so close to them when they were coming to (husband). It was important to see them afterwards."

(2,2,4,8)

Alternatively the same widow explains her feelings about the unexplained ending of bereavement support visits by nurses:

"Well, they must have decided. I never heard any more. Like the last time (nurse) came in, just said ...'goodbye. I'll probably call in later and see you.' But I haven't seen her since. I know they are busy and they have a lot to do.

(Question) 'So, what was it like for you when she didn’t come again?

"Oh, well, I handled it you know. I have my moments. Some days you feel good and other days you feel down."(2,2,5,3)
Another carer who had a need to go over clinical issues related to the illness and death, and her own role as carer, (a commonly expressed need for this group) with the nurse who had been involved in the final few days, discussed her unmet need to discuss important issues with the nurse who had been primarily involved:

"She (nurse) came back three times and each time she couldn't make an appointment. I said I'd love to talk to her. I wanted to talk to her, because apart from what was going on for me, I wanted to find out certain things about mum that I hadn't asked while she was alive. Certain medical facts and what have you. I was very traumatised by the way mum died. Any way, she couldn't make an appointment. It was too difficult and I said OK so we just have to take pot luck. Anyway she came three times and each time she missed me. I was out each time. (3,7,224)

Eventually this carer sought help from an independent counsellor.

The importance of bereavement follow-up being provided by nurses and volunteers who had prior involvement with the family was expressed by twenty-seven carers in this group.

In describing the 'calming' influence a nurse's visits had, a widow clarified the importance of contact with a nurse who had been present at her husband's death:

"It's better to have them call back, because they've gone through the trauma with you, shared it with you, so I think it's better for them to come back as a follow up because they know what it's like." (1,4,6,23)
Alternatively a widow discussed her reasons for not following up the opportunity to have a volunteer visit:

"I would have known that they'd come to help. But there isn't that same liaison because you don't know them and haven't shared these experiences together." (1,6,7,8)

Three carers of the thirty interviewed were receiving bereavement visits from volunteers and considered this support highly valuable. In two of these three situations the volunteer involved had provided carer respite prior to the death. This allowed a natural sharing of important memories to occur. Sometimes carers were confused when volunteers contacted them as they were unsure of volunteers' roles in bereavement:

"I think I might have had a phone call from someone. This is where I get confused between the nurses and counsellors. I can't sort of distinguish between them." (1,9,7,17)

Although carers were supplied with written information regarding the availability of visits and drop-in centres, they expressed difficulty in absorbing this information when it was distributed at times of acute grief.

Following the most highly valued bereavement visits by familiar nurses and volunteers, telephone contact was the next most valued help activity. Telephone contact by volunteers who had not known the deceased was less highly valued by this group:
"She (volunteer) was very nice on the phone. But, it's not the same as having someone face to face like you and I are. It's different. As nice as she sounded on the phone. It's better for me to be able to talk to a person face to face." (1,4,5,9)

Barriers to mutuality in service relationships occurred when multiple service providers were involved prior to the death, contact had been brief, or a firm relationship had not been established. The carer was then less likely to utilise the support available during bereavement. When visits were missed due to carers not being at home when nurses and volunteers called, or when carers were confused about the roles of nurses and volunteers during bereavement, they were less likely to describe visits and calls as beneficial in terms of bereavement support. Cultural differences and communication problems due to language limitations created barriers to the development of mutuality and the involvement of carers in follow-up support. An interview with one widow with limited understanding of English, who had lost her husband seven months previously revealed that she had many unanswered questions about the clinical services provided to her husband. She was confused by her contact with many different service workers during the bereavement period:

"You see ...probably for these people (English) and the Silver Chain everybody in the community...everybody is English. Because this lady is English (volunteer) ...probably in England this thing work. But, for us foreign European people ...I don't think OK." (2,6,6,11)

People who were already at risk of social isolation as a result of cultural or language differences had an increased risk of further isolation, as a result of bereavement.
6.1.1 DISCUSSION - MUTUALITY

Care-giving environments, according to Benoliel (1993), support the integrity of the person by helping them seek meaning in the experience. Reciprocity which contributes to a sense of shared experience is suggested by Benoliel as an element of a care-giving environment. In the experience of death and dying both carer and nurse are providing the dying person with an opportunity to bring a positive closure to life. This fosters the development of a reciprocal relationship. Rawnsley (1990), cited in Benoliel (1993, p. 7), suggests that "... purposeful voluntary bonding can contribute to the actualisation of mutual goals through instrumental friendship." According to Bowlby (1980), traditionally, families close ranks and admit only close friends after a death. Acceptance of nurses as 'friends' into the bereavement environment allowed them to encourage bereaved carers in active grieving. The importance of nurses and volunteers who have provided pre-death support in the initial acceptance of bereavement follow-up by carers is well documented in transcriptions of interviews with this group.

The bonding of nurses and carers developed in the intensely emotional environment surrounding the care of people who were terminally ill as they pursued mutual goals to maintain the health of the carer and patient and contribute to a peaceful death. The mutual goal of 'coping' through the crisis of death is continued into the bereavement environment. This had a positive effect on carers' acceptance of bereavement support services. When volunteers had developed mutuality through shared experience of the events leading up to the death, their support was also more likely to be valued during the bereavement period.
The existential nature of the caring environment in palliative care is discussed by Morgan (1993, p. 24), who suggests that bringing oneself as a person to professional interactions represents a new way of caring. Marcel, the existential philosopher, quoted in Morgan (1993, p. 24), states "there are some people who reveal themselves as 'present' when we are in pain or need to confide in someone, while there are other people who do not give us this feeling, however great is their goodwill." The sense of mutuality of being cared for and caring for each other exists in the immediate period following death as both nurse and carer adjust to the loss of the patient.

Mutuality ensures that each party will give, take, receive, and exchange during an interaction (Curran and Kobos, 1980). It was important to carers to have opportunities to inquire about nurses' well-being and to bring their relationship to closure. The validation of mutual caring roles relating to the care-giving environment prior to the death was also important to carers, who frequently had a need to clarify their role within the illness context.

Operationalising mutuality means accepting a service philosophy in which both quality of existence for both carer and nurse is stressed. In this way, the power balance normally present in professionals' interactions is absent. The development of mutuality in the pre-death phase is determined by the acknowledgment that the carer also brings expertise to the caring environment through their intimate knowledge of the patient. Only when the combination of the person-centred knowledge of the carer, and the clinical knowledge of the nurse is mutually shared, can the quality of care be optimised. It is this exchange of knowledge which allows a mutually holistic approach to the pre-death quality of life for patient, carer and nurse. This mutuality is continued into bereavement and has an empowering effect on both nurse and carer.
Mutuality in the context of bereavement support was most likely to develop when the nurse/volunteers and carer have had consistent lengthy contact prior to the death. The continuation of the relationship into the bereavement phase was highly valued by carers and influenced their perceptions of the value of the service. When multiple service providers were involved prior to the death, contact had been brief and/or a firm relationship had not been established, the carer was less likely to utilise the available support during bereavement. The reciprocal caring nature of the mutual relationship also provided a safeguard to over use of nurses for bereavement support by carers who recognised the dual roles played by nurses in both the clinical and bereavement settings.
Valued 'help activities', their value to carers, and influences and barriers related to the theme MUTUALITY are represented in the following diagram:

![Diagram showing the relationships between valued help activities, their value to carers, and influences and barriers related to the theme MUTUALITY.]

**Figure 2.**

6.2, Bereaved Carers

**Theme 2. Continuity**

(BRIDGING LIFE AND DEATH IN PARTNERSHIP)

Continuity in the context of this research related to the continuity of contact with the caregiver who had been involved prior to the death. The importance of this 'bridge' between
life, death and bereavement personalised in the identity of the nurse-caregiver is captured in the words of a recently bereaved widow with two teenage children. Despite the availability of other social supports she highly valued continued contact with familiar nurses:

"They (nurses) really understood what it was like. What my husband's character was, his personality, and I think that's what makes the difference. We talk about him, where still people today will avoid you and don't know how to cope. I think people are getting better, but we still don't know how to deal with bereavement, and people dying and how to get support."(1,1,8,15)

A carer who cared for her husband and three years later her fiance, both of whom had received Silver Chain Hospice services prior to their deaths, explained the valued experience of bereavement follow-up by the nurse-caregiver following the death of her husband, and by comparison, her unmet need for support following the recent death of her fiancee.

"When he (husband) passed away, they came and visited fairly regularly until I was OK."(1,8,1,24)

In contrast her experience of the more recent death.

"I would have liked to have seen (nurse) and catch up and have a talk about things. I had a lot of anger, and I think if she had been there for me to talk to, it may have helped at the time."

(Question) Did you consider giving Hospice a ring?
No, not really. Well I did know who to ring, because I did have the paraphernalia. They might have tried to contact me and couldn't catch up. She (nurse) did try to ring me once and was going to ring me again that night, but didn't. That was when I would have liked to talk to her."(1,8,4,4)

It was at this stage in the interview that the participant needed to talk to the researcher about the circumstances surrounding death of her fiancé and the 'lost dream' of a future life together. It became clear that she felt a need for bereavement support even although she had a very supportive family with whom she now lived.

The timing of bereavement visits by familiar nurses and volunteers was also frequently discussed by carers. All carers reinforced the value of contact with nursing staff immediately after the death. In response to the probe: "Were there times when you felt you needed more support or less support?" a common response related to the value of visits timed around the four to six week period of bereavement, when support from family and friends were becoming less intense. This need was explained by two newly bereaved widows:

"I was very teary about six weeks after my husband died. At first everyone is coming round. You have too many people, too many callers and the house was crazy in the first weeks. And then everyone stops calling and you stop getting phone calls. A visit would have been good at that time." (1,1,6,9)

"I think the worst periods are the few weeks after the death, because you haven't got into a system. I could see that, if perhaps they popped in a bit more frequently it would have been good. But I realise that the sisters have times when they are so busy that popping in where it's not needed or not physically needed is hard." (1,6,6,3)
For carers who had been bereaved for a longer period of time a common need for support at a particular time was not identified, although three carers of the twenty who were interviewed in this group, expressed feeling particularly 'sad' around the six to eight month period:

"I think probably my worst time was a couple of months ago. That would have been six months after (husband) died and you know, I seemed to feel things hard then. But a part of me seemed to get up and just go on." (2,4,6,4)

Carers' accounts of times of particular need to access bereavement support varied and carers were equally divided in their evaluation of the level of support they had received in the initial stages of grief. Of the thirty carers interviewed, twenty-seven felt that they had benefited from bereavement follow-up. When asked about areas of possible improvement, eleven carers expressed a need to have had more frequent contact within the first few weeks, although this was always accompanied by statements which recognised the more urgent needs, from their perspectives, of the clinical needs of other families. A common need to discuss the death process, particularly when the carer had been alone at the time, or the death had been traumatic was expressed. It was highly important for carers to know that they had done everything possible at the time of death, and to have their role as carer validated by nurses.

"I said to the nurse who was here when he died...well, what do you think really happened? It all happened so suddenly. And, she explained that his heart had given out, and that 'fluid' was the main cause of it all, but other than that there was no other cause. We also had a bit of a chat about the death certificate." (2,4,12,1)
Bereaved carers consistently expressed the value of having 'permission' to freely express their grief in the presence of nurses and volunteers with whom they had already shared anticipatory grief in the pre-death period. Carers who had received visits from volunteers reported on the enabling aspect of this contact. This contact was most highly valued when volunteers had been involved prior to the death.

"(Volunteer) comes and gives me support. She's been coming since we first became part of this situation. She used to come and sit with (husband) while I went shopping. She knows all about our past life and when she comes I can show her the photographs and things like that and she is genuinely interested because she spoke about these things to (husband). It's like having a close friend and I think that helps." (1, 7, 6, 10)

Volunteers represented a link to the 'normal' community for carers who accepted their involvement and reinforced the future expectations of re-entry into community roles without the deceased. Of the thirty carers involved in the study, two had regular contact with drop-in centres. Single visits by volunteers were not as highly valued by carers as more prolonged contact. One carer explains her experience:

"There was someone from the bereavement centre came to see me once, but I don't think 'one-off' is enough.

(Question) What was that like?

It was good because it was good to be able to talk to someone that's interested in what you say. You can talk to friends, and things like that, and they don't really understand. But...I don't think a one-off visit's enough." (2, 9, 5, 3)
When children had lost a parent through death, being able to talk through feelings with nurses was viewed as very helpful by carers, who had few reserves to support their children when they were overwhelmed by their own grief. This was expressed consistently when children or adult children lacked their own support networks. A widow expressed her gratitude for the help given to her young daughter following the death of the carer's mother:

"She, (daughter) was extremely close to her grandmother and was very upset when she had gone. There was one particular Silver Chain nurse she became very attached to. She (nurse) came an extra once or twice to talk to her. She gave her a little butterfly brooch. That's their symbol you know. " (2,9,7,10)

The immediate removal of medicines and equipment was viewed positively by all carers. This, to them was symbolic of the passing of illness from the home and allowed memories of the 'well' person to return. When the deceased had temporarily occupied a room which had belonged to another family member, it was important to re-establish the 'normal' situation immediately.

All of the carers in the third group of participants who had been bereaved for over twelve months, felt positively about receiving anniversary cards to commemorate the death and being invited to the St. Luke's Day Service which is held annually:

"What was nice was that we received a card on the first anniversary which was much appreciated. To think that somebody even remembered " (3,1,3,9)
Continuity of care by known and trusted nurses or volunteers following the death is highly valued by bereaved carers. Barriers to continuity for carers occurred when there was premature and unexpected disengagement by the nurse or volunteer who provided bereavement support. It was commonly expressed by carers that they had been unsure when bereavement visits were no longer being provided:

"No, they didn't actually let me know, but I knew eventually that they would have to stop coming in. They can't attach themselves to people, but they didn't come right out and say 'We won't be back.' I think, maybe, they could have come back a few times, rather than just cut off." (2,9,12,24)

It was important for carers to have an opportunity to finally thank nurses and volunteers for their involvement and support. When volunteers contacted carers unexpectedly, carers felt unsure about the continuing role of the nurse:

(Question) When the volunteer became involved, did you know what was going to happen?

"Not until she rang me and told me she was coming to see me. They must have asked her to take over. When this volunteer rang me up, I got the impression then that I wouldn't see them any more." (2,4,9,21)

When more than one team or more than one service is involved in providing Hospice services e.g. when the dying person is admitted to another service, or staff from a different region are involved due to relocation of the patient, continuity may be negatively affected. This can result in an unmet need for bereaved carers to discuss important aspects of care, and begin working through grief.
6.2.1. DISCUSSION - CONTINUITY

Continuity of care for the carer following the death of their family member, is an important aspect of Hospice philosophy (Saunders et al, 1981; Lindstrom, 1983; Kalish, 1985). The expressed need of carers to continue contact with nurses and volunteers for bereavement support, upholds the view of Martocchio (1985), who discusses the complicating factors of the grief of significant others in the bereaved person's environment and the possible expectations from family and friends which may, in fact, inhibit the expression of grief. Recovery from grief and the strongly related factors of negative pressures from family and friends have also been investigated by Maddison et al., (1968); Raphael, (1980); and Rook, (1984). Bereaved carers consistently expressed the value of the continuation of the relationship with nurses and volunteers into the bereavement period. They felt that they had 'permission' to freely express their grief in the presence of nurses and volunteers with whom, in many cases, they had already expressed emotions in the pre-death period.

Lind (1989), suggests that continuity of care only functions well when it is built into the system and not left to chance. Barriers to continuity are most likely to occur when more than one service is involved e.g. when the dying person is admitted to another service, or relocated to another region. This may result in the bereavement needs of the carer not being met and opportunities not being provided for bereaved carers to discuss important aspects of care, validate their roles as carers and begin working through grief. When the relationship with the nurse or volunteer who had been providing services was not formally closed, carers were unable to conclude their relationship and were confused regarding their service 'status'. Cultural expectations and language problems also presented barriers to continuity.
Valued 'help activities', their value to carers and influences and barriers related to the theme CONTINUITY are represented in the following diagram:

**Figure 3.**
6.3. BEREAVED CARERS.

THEME 3. COLLABORATION.

(DECISIONS IN PARTNERSHIP).

The third theme, collaboration, relates to the equal partnership between carer and the nurse or volunteer who is providing bereavement support. This collaborative relationship, which was established in the pre-death period, allowed equal and reciprocal decision making.

As acceptance of death as a fact of life is inherent in the palliative care system, the decision on behalf of the patient and carer to access Hospice care services demonstrated an acceptance of the terminal nature of the illness and a commitment to openly share in the dying process. This encouraged the nurse, patient and carer to engage in open and honest communication. By providing care in the client's home environment which was removed from service structures in which beliefs and practices may have become institutionalised, the values and beliefs of the caregiver and patient regarding decisions about how they will live, die and grieve were more easily explicated. A widower in his seventies, who was himself in poor health, in recounting his contribution to his wife's care reinforces for himself his ability to 'cope' with her extensive physical self-care needs with minimal assistance from the service:

"They (nurses), didn't have to do much for her at all, as I said she was capable of doing it for herself with my help. So, all the nurses had to do was just sort of stand by and say 'that's right, you've done it right, you know,...that was it.'"(1,3,3,7)
Collaboration between nurses and carers acknowledged that life situations became more meaningful to people who were involved in the decision-making process affecting them. The collaborative process established between the dying person, carer and nurse prior to death encouraged carers and patients to identify their problems and needs. As a result, the relationship between the nurse, carer and patient required a great deal of mutual confidence, trust, and respect. This collaborative effort between the nurse, patient and carer, allowed the patient and carer to maintain an internal locus of control. This affirmed the carer's belief in their capacity to 'cope' with the increasing physical and emotional demands during the terminal phase of the illness. As one widow described her experiences of caring for her husband who had a particularly traumatic death:

"You learn things about yourself as well. It's a learning experience for yourself as well as anything else. The things I had to do for (husband)... I didn't think I could do it, but when you're put to the test, it makes you see that you're really stronger in yourself than you think. So it's a learning experience."(1,4,7,19)

The continuation of the collaborative relationship with the nurses who supported her prior to the death and were currently providing bereavement support was demonstrated in the following self-assessment of her bereavement needs:

"When you're under strain and pressure, you've got to have someone to talk to ... to get rid of the pressure out of you, you know. "(1,4,7,5)

She described her experience of follow up bereavement support:
"They (nurses) were very supportive, very understanding, just let you talk...encouraged you to talk, but they never forced their own opinion, or that, on you. Just left everything to you sort of thing. They were a sort of sounding board, and let you talk to them."(1,4,2,5)

Later in the interview, her confidence in her ability to eventually overcome grief was revealed in the following statement:

"I think you've got to work through it yourself, you know...try and think things through yourself, because you can't let yourself become dependent on ladies like (nurse).(1,4,7,12)

Individual belief in coping which developed as a result of the supportive collaborative model of care, flowed on from the clinical environment to the bereavement stage. In discussing his past and current involvement with Hospice nurses a widower, who shared his initial concern about his ability to cope through the experience of watching his wife slowly deteriorate and eventually die from motor neurone disease, described the support he received before the death of his wife who was fiercely independent and for whom he was primary carer:

"Even before she died, I was so positive about them, you know. If they said we'll be here on such a day, they were. They'd say...if you want us ring and we'll be there straight away.' I've got nothing but praise for them. They were so gentle with her and everything."(1,2,8,14)

In discussing his contact with the service since the death of his wife he stated:
"They are persistent in asking if I'm all right...if I'm wanting anything. Well, it's very comforting really. I haven't had to ring them, but it's nice to know that I've got the numbers to ring and there would be somebody here. They've given me the confidence that they would be here if anything happened."(1,2,9,16)

A widow expressed confidence in her ability to cope with grief and a belief in nurses' ability to provide support.

"I am always happy to see them because I need reassuring that everything's going all right. They know the sorts of things I can expect to feel and to happen, because they've been through it with so many other people." (1,2,2,5)

Throughout the transcriptions from this group, there was frequent reference to the confidence felt that the service could be contacted if required. All participants expressed 'comfort' with contacting the service directly, however, participants also expressed reluctance to do so, due to their perceptions that their need for bereavement support was not as important as others' needs for clinical services. Carers' previous experiences of their involvement during the critical care period, which, in most cases, involved the need for urgent clinical contact, inhibited their utilisation of bereavement follow-up services. This is demonstrated in the following transcripts from interviews with three newly bereaved widows.

"They all told me that if I needed anything I could ring them. But, you hesitate to do so because you know that there are people out there that are genuinely sick and have got sick partners and families. I felt that I tried to cope as best I could without calling these people, because I feel they are stretched to the limit." (1,9,4,17)
"I can't expect her (volunteer) to mollycoddle me forever, she will have other people who need her services as well. I can't take up her time when she's got other people that need her just as much...can't expect her to spend time with me when she's needed elsewhere."(1,7,7,4)

"This is the first death that has been really close to me. Well, I don't suppose I'll ever get as close to this, but for a first experience, its been a shattering experience."

..."If I thought I needed more help, I wouldn't hesitate ringing and getting (nurse) out, but I don't want to allow (nurse) to be a crutch for anyone. I know I have to do it myself."(1,4,9,2)

Information sharing about the possible alternative community supports available to carers was also highly valued by carers, although only four of this group had contacted other community groups e.g. Solace whilst one carer had sought individual counselling.

Although the encouragement to self-initiate the service had the ability to empower bereaved carers and allowed them to control their need for intervention, this also deterred those who did not perceive their needs as being important in the overall context of the Hospice service. At the time of bereavement, the transition of care from the patient to themselves may not have been fully understood, although this is integral to the Hospice philosophy. As a result, support needs may have been ignored by carers. Reference also has to be made at this point to the reassurance felt by carers that there was a service in existence, even if this may not have been fully utilised by them. The comfort in 'knowing' that help could be provided carried many people through their most critical episodes of sadness.
A collaborative approach is also important in the disengagement phase of the service. This emerged as a significant factor in the interviews with groups of carers who had been bereaved for more than six months and who were no longer accessing bereavement support. Disengagement is the term used to describe the termination of formal support by the visiting nurse or volunteer. When disengagement was initiated by the bereaved carer who made the decision that formal contact was no longer necessary, due to their own self-assessment of bereavement status, carers feel a sense of control, and belief in their ability to cope independently with their grief. The decision to disengage, when it is mutually agreed by carer and nurse-caregiver is also valued as a collaborative process. If the bereaved carer is unclear about whether or not the nurse will contact, this was confusing and caused doubts about the carer's self-assessment of their bereavement 'status' and the availability of the service in future.

Collaboration in decision making was also influenced by cultural expectations and language problems between carers and nurses and volunteers providing bereavement support. This had arisen in the situation of one widow who had limited spoken English and had been unable to explain the devastation she felt following the death of her husband, as this had been preceded by the death of her only child two years previously. She had no other family support. In discussing the confusion she felt with the many different 'visitors' who tried to support her in the few weeks after her loss she said:

"Close the door and not see anybody. I see nobody ...much better, because the people I see ...no understand you. They say 'goodbye....see you next time '...but another person come...you don't know how to telephone. They ask the same question again and again." (2,6,8,1)
The importance of learning shared leadership, shared planning, decision making by consensus, and empowerment of self and others is stressed by Lind (1989) when describing her work as a hospice nurse. She suggested that collaboration as a way of creating a care-giving context for work, empowers both providers of services and those who receive them. The collaborative partnership between nurse and carer was established at the time of the initial decision by the carer and ill person to commit themselves to home based terminal care. When the carer and ill person are empowered within their own environment and are not subjected to institutionalised values, a partnership was established which honoured the contribution of carer, ill person and nurse as equal partners in the decision making process. The continuation of this partnership into the bereavement period was also an empowering process for carers, who had, as result of the traumatic circumstances surrounding death, also experienced personal growth and belief in their personal coping abilities. Reflection on their role in the care of their family member, strengthened their belief in their ability to survive grief.

Lattanzi (1988. p. 81), in discussing the accomplishable goals of bereavement follow-up suggested that it was important to ..." provide family members with information about the process of grief and an opportunity to review and reflect upon the experience of caring for their loved one and their loss experience."

Lattanzi also suggested that the availability of bereavement support, helps on a symbolic level to counteract the feelings of abandonment and isolation which characterise bereavement. Narratives of bereaved carers strongly reinforce the security they felt in the knowledge that the service was available. It was, however, important to carers to
determine their personal needs for support and be responsible for accessing the service, although this could also be detrimental for those who placed little value on their personal need for support compared with other families who had yet to cope with death. All bereaved carers, even those who had not felt a particular benefit from bereavement follow-up, were reassured that, should they require help, a service was available to them. The knowledge that support would be available in the future if required provided carers with an important safeguard against feelings of loneliness, isolation, and fears about their future.
Valued 'help activities', their value to carers and influences and barriers related to the theme COLLABORATION are represented in the following diagram:

![Diagram of COLLABORATION]

**6.4. NURSES THEME 1**

**CONCLUDING CARE**

(BRIDGING LIFE AND DEATH IN PARTNERSHIP)

Concluding the care was the strongest theme from this group of participants. Embracing the hospice philosophy of caring for the care-giver following the death, was a
characteristic shared by all participants in this group. It was a common characteristic of this group to have experienced dissatisfaction with the way death had been dealt with within institutional environments such as public hospitals. The need for nurses to conclude their relationships with care-givers during the bereavement phase was consistently related to nurses' job satisfaction and their perceptions of having delivered a valued service.

"I find it very satisfying to follow up the families. I think I'd feel that I was only doing half the job if I did only the clinical area and didn't see them afterwards. Yes, that would be a big loss I think." (4,9,11,24)

"The death of a patient is, if you like, the end of caring for that person, but there's a new care that goes on for the bereaved that you've come to know. You've picked up on issues over the time you have been going in, and I think it's very important for the nursing staff to finish that off, and for me personally, I like to go back." (4,7,5,3)

The term 'reward' was consistently used to describe nurses' experiences of returning to carers who had valued their services during the illness phase. The nature of the relationship prior to the death, also impacted on the nurses' perceived ability to provide follow-up support. Bereavement support which was provided by nurses who had been involved in the illness phase, was perceived by nurses to be most beneficial to carers. A nurse explained:

"It is really important that it is the same person because they can relate to you and to what's happened beforehand. There might be ongoing issues the family want to discuss about how the patient died. They often worry about issues afterwards and like to talk
about it to someone who knows. It is also important for me to find out how they are coping with bereavement." (4,9,4,23)

"...especially if it's been a long term patient...one you have looked after for a long time, the feedback makes you feel good and makes you think...well, I did a good job, they are really pleased with the way things went. Then it is easier to give them support." (4,6,2,2)

In describing their relationships with carers, nurses frequently referred to 'friendships' which had developed in the care-giving environment, whilst they also perceived the relationship as professional:

"I think our service is a very personal service and people can become very close to us. The other danger is that they could become dependent, but I think everyone is professional enough not to let that happen...and we're too busy to let that happen anyway." (4,10,8,5)

References to a 'healthy' and 'satisfying' conclusion of care consistently appeared in transcriptions of nurses' interviews, with follow-up contact being described as an important 'ritual' for nurses. Nurses' perceptions of their own emotional health, as it related to a satisfactory conclusion of their relationship with carers was explained by a nurse who had been with the service for five years. The importance of concluding a particularly close relationship which had developed with the patient and patient's wife was described:

"Most of the time it's concluding the care, making sure things are OK. I think it's important for me and my emotional well-being to conclude the relationship." (4,1,5,21)
Although interview data strongly indicated that nurses perceived bereavement support as equally important as clinical nursing services and that it was important to conclude the relationship with carers, bereavement support was also considered by nurses, as a service requiring special skills. One nurse commented on her feelings related to previous involvement with bereavement follow-up:

"It was scary. I don't think that I did it very well, but it was easier with people you already knew because you could talk about the person who'd died. I guess I got better at it as I went along, but I never felt completely capable. I don't think everyone who is suited to giving critical hospice care is also suited to bereavement follow up." (4,2,14,8)

Contact with the family following the death, however, despite feelings of discomfort in the bereavement support role, was considered extremely important by all nurses. The feeling of discomfort in meeting families' needs was most likely to occur when the relationship between nurse and carer was not well established and when contact during the illness had been brief. A nurse discussed the comparison between having known a family for a long time and having only brief contact before the death:

"There's a great deal of difference. The longer you have the patient, the more you get to know the family and the more comfortable you are with them. Sometimes you almost regard them as friends. When visiting the carer of a patient that's been a short term admission, you have this kind of detached feeling. It's really hard. There is not the same rapport. Not the depth of relationship."(4,6,4,1)

Another nurse described her difficult experience of carers rejecting bereavement support. In both cases there had been problems with establishing a close relationship with the families prior to the death:
"I can remember one example. They were very isolated people, didn't socialise and didn't know their neighbours. We were seen as outsiders coming in and although we had been welcome in the short term, we definitely weren't welcomed afterwards.

I can think of another example as well, where we weren't shooed away rudely, but it was clear that we were made to feel that we needn't bother." (4,4,18,12)

Despite descriptions of 'close' and 'friendly' relationships between carers and nurses, nurses were also aware that their role was a professional role and that it was necessary to conclude contact with carers in order to meet the demands of new referrals. Varied descriptions of how the service was concluded by nurses and the process of disengagement, indicated that there was considerable flexibility according to nurses' assessments of each situation. Some nurses were guided by the approved service guidelines whilst others relied on their own assessment of the carers' ability to cope. This allowed for flexibility in meeting carers' needs. Nurses were inconsistent in their description of a 'cut off' point for bereavement follow-up and preferred to keep in contact with carers until they were satisfied with carers' situations:

"Usually it's six months by the time we all get round to actually doing it. Sometimes you get so busy that you don't get on top of bereavements. I have to feel comfortable. I wouldn't cope with closing a file if I didn't feel comfortable." (4,5,11,4)

There was also comment from nurses that the service time frame was constraining and did not allow for meeting individual differences in bereavement situations. Nurses generally used their own judgement both in the nature of the support they delivered and the duration of contact with the carer.
"I always felt that things were too regimented and I always felt pressured by dates. Then for every day after the date I think you feel guilty...you feel rushed and you don't do it very well." (4,2,11,2)

Although it was uncommon, nurses reported that contact with carers could extend long after the 'approved' duration of service. Four nurses described particular situations when bereavement follow up had extended beyond twelve months. Closure of the service was most highly valued by nurses when this had been a joint decision between nurses and carers, or when carers had initiated closure. Two nurses described what for them was a typical way of disengaging from providing support:

"Generally speaking, they will say to you that they are all right and they are looking OK. You can identify what's going on with them physically e.g. sleeping, eating, and that they're not concerned about financial things. They will actually say that they're all right...so it's for them to identify that they are all right."(4,9,6,10)

"Basically I ask them how they're feeling about it, and if they're feeling comfortable about it...and then I say ...let's look at closing it next time we meet. But, I always leave the door open." (4,3,5,1)

The most consistent barrier to concluding care in providing bereavement follow up was time and workload constraints. This was a major stressor for nurses who felt guilty when they were unable to meet service expectations:

"What I see is that when we get busy, the bereavement is left. It would be easier if we had more time to do it and then it would be done properly. I used to feel guilty about not doing it when you see their names there and you think I really should do something about
this. But, if you're already trying to work a nine hour day with current patients, they end up taking your priority. So... maybe if funding were different, where we were truly funded to include bereavement follow up, then we would really give them better service."

(4,2,12,1)

"We are getting better at it, but I'm afraid that when you're busy with the hands on.... the ones who are physically dying, the bereavements do get forgotten." (4,7,20,6)

Particularly stressful situations for nurses arose when there was some personal relevance between the life situation of the bereaved carer and the nurse's own life circumstances. When nurses became deeply involved with carers it became difficult for nurses to close the relationship with carers. A nurse who co-ordinated bereavement support for one base described the problems of nurses' identifying closely with the carer's life situation:

"Sometimes you get very close and you really feel the loss personally. Sometimes people get so entrenched and it's hard to stop because the patient has built up such a relationship with that nurse. Sometimes, as I say, it's because of the rapport and the trust that there's no way that you can pull that nurse out. But as long as they can see it's going to cost them something ... you know." (4,7,18,1)

Referral to volunteers was highly valued by nurses who considered that volunteers had an important role in concluding care. Personal communication with volunteers regarding carers' needs was most highly valued by nurses, and face-to-face contact between volunteers and carers once the referral had been made was preferred by nurses.
"I feel that the first visit by a volunteer should always be face to face because the clients
don't always know the volunteers. They know us and they can put a face to our name.
When a bereavement volunteer contacts them it's an unknown voice on the end of a
phone. I think that they can miss things by making contact via the phone. I would like to
see the first contact made on a personal basis." (4,6,14,4)

A nurse offered a suggestion on how a smooth transition to volunteers could be achieved:

"There are so many people from Silver Chain come in, and they can't quite work out
sometimes who is who. It would be a good idea for the primary nurse to take the
bereavement volunteer in, and then they could see that you're really working together.
They might then be more receptive to volunteers." (4,6,17,12)

Some nurses, who had been involved in introducing volunteers to carers prior to the
death, felt that this facilitated volunteers' involvement in bereavement follow-up, whilst
others felt that the introduction of another person at a time of great family stress may be
counter-productive.

6.4.1, DISCUSSION - CONCLUDING CARE

Relationships formed with carers in the illness phase have a significant influence on
conclusion of care by nurses. The types of relationships described by nurses in this
group epitomised what Trygstad (1986, p. 328) refers to as 'professional friendships',
which allow for honesty and open sharing of feelings and knowledge. The conclusion of
the caring relationship allowed for both a fulfilment of nurses' values and beliefs about
the way their service should be delivered and positive self-appraisal by nurses regarding
their roles as 'hospice' nurses. Job satisfaction for nurses was closely linked to continuation of support to bereaved carers in the early weeks of bereavement. Nurses and carers had shared an intensely emotional and intimate life event with carers and the trauma of the death had an effect on both carer and nurse.

The need to conclude the care is also confirmed in a phenomenological multi-subject case study of five hospice nurses by Eakes (1993), who discussed the importance of follow-up contact with families from nurses' perspectives. Stress arising in hospice nurses who were denied a sense of closure has also been reported by Gray-Toft and Anderson (1986), and Fisher (1991). Allowing carers control of their bereavement care was considered important by nurses, and a collaborative approach to disengaging from contact with carers was consistently described as the most satisfying for nurses.

In certain circumstances, however, nurses had difficulty closing their relationship with carers due to a high level of personal involvement. According to Fisher (1991, p. 178), "Nurses may become attached to patients through involvement with their psychosocial or spiritual care and therefore make an emotional investment." Raphael (1980), also discussed the personal investment made by people working in terminal care, and suggests that working with dying and bereaved people heightens mutual empathy and identification as the experience of loss is universal. This view was reinforced by Bowlby (1980) and Parkes (1972), who discussed the pain of witnessing death and bereavement in others and the sense of impotence felt by people who had prolonged contact with those who were dying or bereaved.

An important support in the conclusion of nurses' involvement with families was the availability of volunteers to provide ongoing bereavement support for carers. Volunteer
involvement was highly valued by nurses and allowed nurses to feel that they could share the load with respect to bereavement support, when clinical commitments were high or when support could not be provided by nurses for other reasons. The referral process between nurse and volunteers was most highly valued when nurses made direct contact with volunteers regarding carers' needs. Barriers to concluding care were also strongly influenced by the relationship which nurses had developed with the family during the illness phase. A close relationship could result in both a positive self-appraisal at the conclusion of the service and alternatively in difficulties of closure if the relationship had become more involved. If a therapeutic relationship had not been established, follow-up support may not be accepted by carers and this could also cause a minimising of nurses' feelings of satisfaction with the overall service. Other barriers related mainly to time constraints and workload.
Valued 'help activities', their value to nurses, and influences and barriers related to the theme CONCLUDING THE CARE, are represented in the following diagram:

![Diagram](image)

**Figure 5.**
6.5. **NURSES THEME 2**  
**RESOLVING LOSS**  
(LETTING GO AND REINVESTING)

The second strongest theme emerging from nurses' transcripts related to resolution of the grief nurses experienced through the loss of a patient. As grief is a natural response to loss, nurses who work with people who are dying and those close to them are exposed to experiences which may lead to a grief response. This is explained by two nurses:

"If you've been with them, yes, you've shared what they've gone through. You've felt (this might sound a bit corny), you've felt their pain and actually almost been in their shoes. Not quite to the same extent...but almost, yes."(4,4,4,18)

"I think that's some of the reasons our service is so good. We can support our patients afterwards, as well as supporting ourselves because we are also bereaved with the person. Particularly if we have been very closely involved with them."

(4,10,3,1)

Bereavement follow-up was cited by nurses as a helpful, though stressful, strategy in achieving the resolution of grief associated with the death of their patients. This facilitated acceptance of the reality of the death and also allowed for the mutual sharing of feelings associated with the loss.

Follow-up contact with families was also associated with the expression of appreciation by family members and validation of the important role nurses had played during the
illness. In addition it was common for nurses to receive additional support from carers in the resolution of their grief. As a nurse said:

"Generally if the relationship has been close, I would say that they often seem to almost protect you. They want to you to feel right too." (4,4,6,18)

The memory of the deceased often remained with nurses despite the need to disengage with families and reinvest in new families who were in need of clinical care:

"You miss going in to that family if you've been going in on a daily basis. There is a sense of loss. You miss being welcomed by them and getting positive feedback that they value you caring for their relative. But, it soon goes. When that one's gone, another one takes their place. It doesn't last very long. Only occasionally." (4,6,19,12)

When nurses had become deeply involved with families in the illness phase, it could result in greater difficulty in the resolution of their grief and ability to close relationships.

Peer support was also cited as a major influence in supporting nurses' resolution of their grief. This was reported to occur at a team level and an individual support level. Nurses reported a heightened awareness of other team members to nurses who were experiencing particularly difficult deaths and bereavements. The therapeutic milieu of the working environment was a very highly valued attribute of the service from nurses' perspectives. Two nurses described the supportive environment within their teams:
"I certainly get support when I need it. I come back to the base and get support from the nurses, doctors and counsellors. In all the years I've worked, I've never felt that I haven't had help from somebody." (4,5,3,24)

"Within this base the people are extremely supportive. If you do happen to mention to them that you've had a difficult situation, you can talk it through with them" (4,4,8,11)

6.5.1. DISCUSSION - RESOLVING LOSS

The fact that nurses view relationships with patients as an important part of their nursing care is shown in studies by Hockey, (1976); Field, (1984); and May, (1990). The contextual characteristics of a hospice home care environment allowed the nurse participants in this study to develop caring relationship which were not restricted by the institutional and often technocratic interactions characteristic to the public health systems. As a result, equal and reciprocal relationships could develop between carers and nurses in the illness phase which continued after the death and which could impact on the resolution of nurses' grief.

It is widely acknowledged in bereavement literature that people must disengage from the deceased in order to invest in new relationships (Bowlby, 1980; Parkes, 1972; Raphael, 1980). It is particularly important for this reinvestment to occur for nurses in the hospice environment due to the acute nature of the service and the growing demand within the community for home based care to families of people who are terminally ill. Although follow-up visits to families by nurses who had been involved prior to the death, placed extra pressure on nurses who were busy with acute clinical care of other families during the illness phase, it was also evident, from nurses narratives that bereavement visits also
played a valuable role in nurses' work of resolving their own feelings of loss associated with the death of their patients, and also the loss associated with the closure of their contact with families with whom they had shared a significant life event. According to Eakes (1993, p. 245) "...the nature of the relationship established with the dying patient and family appeared to be central to the nurse's ability to achieve resolution of her grief." The mutual concern between carers and nurses related to their recognition of sharing a loss, was highly valued by nurses and allowed nurses' roles in the provision of services to be validated.

The existential anxiety aroused in the personal death awareness for people who work with people who are terminally ill is discussed by Worden (1983) and Bowlby, (1980), who believed that occupational exhaustion occurs frequently among people who work in the helping professions. The need for palliative care nurses to work through their grief is discussed by Kastenbaum, (1969) and Fisher (1991), who suggested that nurses are as vulnerable to experiencing unresolved grief as other people and required time to grieve. Time to grieve, Kastenbaum suggested, would allow nurses to develop their individual grief coping styles and prevent 'professional burnout'. Vachon (1987, p. 159), however, concluded that hospice staff are not necessarily more stressed than other nurses and that they may have a wider repertoire of methods of dealing with stress. Also according to Vachon, who interviewed over three hundred people who were involved in the care of terminally ill people, the most important environmental coping mechanism was the sense of belonging to a team who worked towards mutual goals and who knew how to support each other. She states that for palliative care nurses "Social support from one's colleagues and team members is a crucial part of coping with job stressors" (Vachon, 1987, p. 217). The growth potential in grief and grief's healing potential is also discussed by Marris (1986) who believed that ensuring that palliative care
environments allowed for the facilitation of staff grief, promoted personal development. The ability to share feelings with colleagues at a time of personal stress and in times of crisis was the most highly valued support mechanism reported by nurses in this group which upheld the views of Vachon and Marris that peer support when working with people who are dying and bereaved is an essential element of the service. Studies by Zimmerman (1981) and Parry (1989) regarding the utility of formal support groups for hospice nurses have reported that these strategies have variable success. Parry, (1989) also discussed the need to adopt flexible responses to team members' stress by creating an environment of mutual helping behaviours. Nurses did not perceive that they had a need for formal counselling, but highly valued the informal support offered by other team members citing this as serving an important function related to their ability to cope with the ongoing emotional demands of the work.

Team ethos at base level, according to nurses, allowed for different means of communicating and relieving stress and this not only contributed towards stress relief, but was also a source of job satisfaction for nurses. Stress related to patient loss was most likely to occur when the pre-death contact had been intense and of long duration or when nurses were involved in situations which had personal relevance to their own life's experiences. If nurses had a particularly involved relationship with a carer prior to the death, their own grief experience may interfere with their ability to provide support to carers. When this occurred and was recognised by the nurse, other team members became involved in carer and nurse support.
Valued 'help activities', their value to nurses and influences and barriers related to the theme RESOLVING LOSS is represented in the following diagram:

![Diagram showing nurses theme 2: Resolving Loss]

**Figure 6.**

### 6.6. Nurses Theme 3

**Developing Confidence**

**(Belief in Knowledge and Skills)**

Developing confidence in the bereavement support role was the third theme consistently present in nurses' transcripts. Interacting with carers and evaluating their needs in the
bereavement phase required not only theoretical knowledge, but experiential learning. There were three sub-themes to developing confidence namely, education and training, experience, and intuition. Each sub-theme will be discussed separately.

i) EDUCATION AND TRAINING

The education on grief and loss which the service provided was highly valued by nurses who perceived theoretical knowledge as essential to their feelings of confidence in providing bereavement support. As well as participation in workshops and seminars which had been organised by the service, nurses were also self-directed in their learning and some had participated in further education in the area to enhance their understanding of grief and loss:

"I've done some formal training. I did three units of psychology at university as well as being involved in in-service lectures. I've studied for the last six years to learn more about it." (4,6,2,13)

"As well as attending courses, there's been any number of books that deal with bereavement I've read. I think it's important to keep learning on-going."(4,1,2,14)

Two nurses expressed a desire for further education sessions at a base level:

"I think staff need to keep education skills up in the area of bereavement. We are doing something here to address it, I hope, and we have got enthusiasm for it."

(4,7,25,8)
"We could all do with more counselling skills, more workshops where you actually use your skills. I know there are courses being run but they are limited to one or two people from each area. I'd like to see things done in the base among the team, so they can improve their counselling skills." (4,6,18,14)

ii) EXPERIENCE

Experience was the factor consistently described by nurses which most influenced their ability to provide support services which they felt were adequate. Nurses described their initial discomfort in their initial contact with bereaved carers, even in some cases, avoidance of bereavement visits due to their perceptions of being unable to provide tangible assistance. All nurses interviewed stated that their feelings of competency were highly influenced by building confidence through accumulated positive experiences of carer contact during bereavement:

"I've read books which discuss bereavement, but I think the majority of my developing skills had been through experience. Getting an idea about where people are at before their partner dies, seeing how they are coping and using those parameters." (4,1,9,23)

"When I first started at hospice it was very difficult because I didn't have any experience in providing the bereavement support and I felt that I didn't do the job very well in those days. I've been at hospice for over six years now and it's probably only in the last two or three years that I've felt comfortable with visiting bereaved people. Getting feedback from the relatives of people you've cared for, makes you feel you've done a good job and they are pleased to see you come back after the death."(4,6,1,5)

Ongoing and regular contact with bereaved carers allowed nurses to develop personal measures of how situations were developing for carers and allowed them to assess the
level of support required according to their own interpretation of each situation. The confidence which accumulated from experience, which was reinforced by positive feedback from carers, dispelled nurses' feelings of discomfort in bereavement support.

Nurses also reported that their personal experiences of loss, helped them to identify with the needs of carers during bereavement:

"I think I drew a lot from my experiences of the deaths of my father and mother. My experiences of that, I think, helped me develop a sense of understanding what people were going through." (4,7,2,4)

Experience of the bereaved family prior to the death was also an influence on nurses' confidence in bereavement. When contact had been brief, or there had been difficult relationships within the family, nurses felt less confident in providing support.

iii) INTUITION

The development of an intuitive evaluation of carers' needs was consistently expressed by nurses. Intuition, refers to the development of a knowledge and expertise in the evaluation of bereavement situations which could not be attributed solely to formal education or experience. Nurses described this as a 'sense of knowing' when carers were either coping with their loss or required extra support. Nurses attributed intuition partly to their knowledge of the carer and the carer's ability to cope, which had developed as a result of contact during the illness phase:

"You can't start talking too much about the future until they're ready to proceed. You can't do that. You have to feel your way and use your intuition. There have been
situations when I've continued to visit because I've felt intuitively that's it's not the right time to pull out and that there are more issues and that they're not coping." (4,6,10,9)

"There is a sense of knowing. But it's an intuitive sense. It isn't these sort of objective criteria that I'm going to follow, and when you've reached this point, then you're 'well.' ...and 'goodbye'." (4,3,6,5)

Intuitive sense in conjunction with experience and theoretical knowledge, allowed nurses to confidently evaluate both the carers' progress and their own involvement. This influenced their sense of satisfaction with the service and their personal coping ability when positive outcomes for carers were not attained.

"You can't take everything on board. There are a lot of things you can't change anyway. Sometimes people don't want you to help, and so I just have to let it go. I feel OK about that now." (4,5,15,14)

6.6.1 DISCUSSION - DEVELOPING CONFIDENCE

According to Vachon (1987, p.180), as care-givers learn their jobs they develop some sense of personal control over what they are doing. Vachon identified education as one technique to enhance competence and reduce stress in working with people who are terminally ill and bereaved. Nurses developed confidence in bereavement support over time. A combination of education, training and experience underpinned nurses belief in their ability to provide bereavement support. Nurses in this group, set goals for themselves, had frequent tests of their competence in their interactions with carers and developed security in their roles of bereavement support. Eventually they were able to
report feeling more at ease due to a sense that they had an increased competency in the bereavement situation. Nurses also had the ability to develop an intuitive sense in relation to the bereavement status of carers with whom they had come to know during the illness phase. Intuition was particularly valuable to nurses in situations where they had become familiar with carers' coping abilities and reactions to stress.

According to Benner (1984, p 41) "... nurses accrue clinical knowledge over time and lose track of what they have learned." The hybrid of theory and experience, according to Benner, facilitates nurses' interpretations of situations, and, as a result, their judgement become more astute. For some nurses it took years to develop a feeling of 'comfort' with bereavement. Once developed, however, nurses experienced satisfaction in the knowledge that they had the necessary skills to support carers.

The availability of ongoing workshops where practical skills in bereavement support could be further developed was highly valued by nurses although the timing and location of workshops, they said, sometimes excluded their participation. Not all nurses, however, despite long exposure to bereaved carers, felt comfortable and competent with bereavement. This could be accounted for by the less tangible outcomes from intervention in this area in contrast to clinical nursing outcomes in the illness phase. Identifying the special needs and supporting nurses who do not feel competent in this area, requires to be addressed by the service. Barriers to the development of confidence related to individual nurses' needs for further training, and the provisions of training at a time and location which they could easily access.
Valued 'help activities', their value to nurses and influences and barriers related to the theme DEVELOPING CONFIDENCE is represented in the following diagram:

**NURSES**

**THEME 3.**

**DEVELOPING CONFIDENCE**

(Belief in knowledge and skills)

**VALUED HELP ACTIVITIES**

- Education and training workshops.
- Prolonged 'on the job' experience.
- Self-directed learning.
- Positive feedback from carers and peers regarding support role.

**VALUE TO NURSE**

- Confidence in skills to evaluate grief experiences of carers.
- Confidence in bereavement support role.
- Development of intuitive sense.
- Positive self-appraisal.
- Job satisfaction.

**BARRIERS**

- Time constraints.
- Availability of ongoing educational workshops. (location and timing).

**INFLUENCES**

Nature of service experiences and personal loss experiences.

Figure 7.
6.7. VOLUNTEERS' THEME 1

CONNECTING

(CONTACT FOR A PURPOSE).

The theme connecting was the strongest theme emerging from transcriptions of volunteer interviews. This theme related to both the volunteers' interactions with the hospice team and interactions with bereaved carers. Four sub-themes of connecting are:- responding to hospice needs; responding to carers' needs; linking; and disengaging. Each theme will be discussed separately.

i) RESPONDING TO HOSPICE NEEDS

The strongest sub-theme in the theme of connecting related to the initial decision made by volunteers to respond to the organisation's need for volunteer involvement in both caregiving and respite roles in the illness phase, and bereavement follow-up. It was consistently revealed that volunteers in this group had chosen to become involved with hospice services, as a result of personal experiences with death and dying.

"I had experienced it in the family. My youngest daughter married a beautiful man who died of cancer. I became very interested in thinking what I could do to help my son-in-law, and when I retired I got in touch with Silver Chain to give my services in any way I could to help." (5,1,9,7)

"My mother had been sick and I had Silver Chain services as I nursed her at home until she died. After she went I thought it was something I wouldn't mind doing, looking after other people. I had never done anything like that before and so I got in touch." (5,8,1,26)
Equally important in their decision to respond to hospice's need for volunteers, was their perceptions that the service was worthy of their involvement and that the nature of the work would be personally challenging to them. Also, the reputation of the service within the community allowed volunteers to maintain valued social roles by association with a service which enjoyed high status within the community.

"I had a friend who died, and I know how well she was cared for, and I thought...that is what I would like to do, but I had no idea what it entailed. The orientation was very intense, but I found...yes, I can manage that. I have volunteered for a lot of things, but they didn't have the right feel until I joined hospice." (5,6,1,5)

"I think it's a wonderful thing that people don't think they are forgotten about. And, honestly, all the people I have been involved with have just spoken so highly of the hospice care service, they really have." (5,4,10,20)

"More and more people are finding out about hospice and you know that you're doing a good job working for hospice. People think it's a wonderful organisation." (5,9,15,9)

Communication with team members was an important aspect of volunteering and volunteers considered structured opportunities to meet with team members and report on their work as integral to fulfilling their role as volunteers. Strategies which had been introduced to provide more structured communication and referral procedures were viewed positively. Volunteers highly valued the availability of other team members to advise them and never felt that they were without support, although the autonomy of their roles in providing home based support was also important to them. Two volunteer explained their views:
"I wasn't happy with the way things were while we didn't have monthly meetings because I felt I was in no-man's land and the only way I was getting support was by ringing the nurses and they are so busy. I find that now they've gone back to the monthly meeting I'm a lot happier because it's a group, and you can discuss things. You are face-to-face with others that are doing bereavement and they can put forward their ideas as well. I feel much happier now than just being here on my own." (5,2,22,12)

"There are times that you just draw blank with bereavements and when you go back to the meeting you find out that the nurses have found the same thing, and they can advise you what to do. So there's a protection there with having a meeting." (5,2,17,1)

The availability of experienced volunteers to discuss difficulties in the bereavement situation was also valued by less experienced volunteers:

"You are supposed to find someone, another volunteer you can unload to when things get a bit much. The older volunteers are usually designated to be that person, so that you can ring up and ask for help and find out if you're doing the right thing." (5,2,23,25)

Direct communication either verbal or written also reinforced volunteers' perceptions of their value as team members by nurses and other staff. Volunteers valued the expectation that they would provide written documentation to the service related to their contact with carers. This was a source of job satisfaction for volunteers, reinforced their value to the service and subsequently enhanced their commitment to their roles. Being attached to a particular nurse and being introduced by a nurse to the carer was also a positive strategy from volunteers' perspectives. This helped validate the volunteer's role with carers and established them as a future contact for bereavement support:
"What they have started this year which I think is excellent, is asking volunteers to go out with nurses on a shift, and so if you happen to get one of those patients for bereavement that you have actually met before, it's easier because they know you." (5,4,20,9)

ii) RESPONDING TO CARERS' NEEDS

Connecting with bereaved carers and responding to carers' needs to discuss their grief was described as highly satisfying for volunteers who developed confidence over time in their ability to provide support to carers. When volunteers had been involved during the illness phase as respite care-givers it was important for them also to be involved in bereavement follow-up:

"When I had been doing relief home care and when the person died, I just wanted to do more. I felt I would just like to go in and listen. There was still a lot of unfinished business for me. If you got involved with the family, then doing the bereavement, you just sort of finished the whole thing off." (5,2,1,6)

All volunteers in this group felt more comfortable contacting bereaved carers when they were already known to them:

"It's easier when you have known the person. When the bereaved person is telling you things about them you can relate that to the person you have known. It's easier to talk with them then." (5,5,14,8)

In comparison, when there had been no contact with the carer prior to the death, it was more difficult for volunteers to be involved in bereavement follow-up:
"When we have known the family before, all the family know what you're doing there, and it's so much easier to be able to help them. But, when it comes to going in cold, I don't like it, and a couple of times I have stopped doing it. I feel duty bound to take my turn but I don't like being the one to go in when I don't know the person. I feel as if I'm prying into that person's life." (5,3,18,2)

Volunteers reported that bereavement follow-up with unfamiliar carers was mainly by telephone contact. Volunteers used different strategies when connecting with carers. Telephone contact and subsequent offer to visit was the most consistent method of responding to carers' needs. At times, however, volunteers experienced a reluctance on behalf of carers to have face-to-face contact:

"A lot of problems arise with getting in to visit in the first place. You'll ring them up and they'll say 'no, I'm fine' ...and then they'll go on to talk for a good hour or more and they do have problems but they are still reticent about having a visit. Because they can't see you, they don't know what you're like and they prefer that voice on the phone. Some people are not terribly interested if you say you're a volunteer and so they clam up and say 'no'." (5,1,4,15)

If, however carers responded positively to volunteers' offer to visit and face-to-face contact followed, this was highly satisfying for volunteers. Other volunteers, did not contact by telephone before visiting carers and found this the most successful way of providing the service:

"I have found everyone absolutely wonderful, but I think that when you knock on that door, you have got to sell yourself and let them know that you are there for them. Not for
youself, but for them and you have to listen to them and then they will trust you.” (5,5,6,14,)

Strategies used by volunteers to connect with carers were dependent on the beliefs of individual volunteers and their feelings of comfort in the bereavement role. The usefulness of volunteers' roles in bereavement was perceived by volunteers as providing an opportunity for carers to have a support person independent of carers' family networks which may exert negative pressures on carers due to unrealistic expectations of recovery from grief:

“You find that with some people, their friends and their family have decided what stage they should be at and they say, 'well... we don't want to hear about it any more.' Whereas a volunteer going in is someone they can talk to.” (5,2,9,8)

“I have a lot of people saying, 'oh, it's just wonderful that there is someone I can talk to who will listen.' A lot of their friends don't want to hear about it and they tell you things that really were very private. I found that a lot, that they couldn't bring themselves to telling their friends even although they had close relations with their friends and family.” (5,8,12,3)

Volunteers remained involved with bereavement support services as a result of receiving positive feedback from carers and team members related to their roles. Volunteers also self-evaluated their involvement with carers and developed a belief in their personal value to the service and their ability to fulfill the role of volunteer.
"When there's a death, people are left with an awful void. For me, it's the value of being able to go in and listen. I'll say, well, look, I'm here and I'll listen. You are an ear if they want to get anything off their chest, or if they feel they're fumbling in the darkness. The person who is left, they have really died as well. I find it very satisfying to know that I am able to help." (5,6,14,6)

Volunteers also perceived the importance of bereavement support in the overall context of hospice services and their role in fulfilling a need that nurses had previously provided:

"The bereavement is, I think, a particularly important part of hospice because there is such a big input prior to the death. The patient dies and suddenly they withdraw all the gear. The notes are taken away, the nurses aren't coming every day and that's another grief for the family if they have had lengthy input." (5,6,16,9)

It was consistently expressed by volunteers that their role was facilitative and that encouragement of carers' expression of grief and facilitating the recovery of carers' self-help skills were critical factors in bereavement outcomes from volunteers' perspectives. The shared responsibility between carers and volunteers to invest in the bereavement support process, allowed carers to control the frequency and nature of support according to their own perceived needs. Although this may have resulted in carers not accepting services, which, from volunteers' perspectives, may have been useful to them, volunteers were able to overcome concerns related to carers' unwillingness to accept relevant help, by adopting a philosophy that volunteers had fulfilled their roles by offering support. Even when volunteers' skills had not been fully utilised, therefore, they were still able to feel positive regarding their involvement by having followed through on service delivery expectations:
"Well, I just go in socially on the first visit and wait for them to bring things up. If they request it I will go in again, but only if they request it." (5,7,11,3)

Common problems were expressed by volunteers in responding to carers' needs. Three volunteers expressed difficulties with providing support to male carers who, according to the volunteers involved, had difficulty communicating their needs, accepting support, and expressing their grief:

"I think a few men especially, are terribly annoyed because, perhaps their wives are younger and then they die and the husband is left. They are terribly worried about how they are going to cope. I find men generally more difficult, really." (5,10,13,1)

Carers from different cultural and ethnic backgrounds also presented with particular needs which volunteers found more difficult to fulfil:

"There was one Italian lady who had very limited English. I tried just saying a word or two and not bamboozling her with a whole long sentence so that she could understand me better. There were some things I couldn't understand but I did manage to get back to the base and let them know that there was a language difficulty." (5,7,21,2)

"My first bereavement was an Italian lady who was in very much need of support. At the first visit, she cried, laughed and went through all the gamut of emotions. I found, though, she expected me to go in for weeks and weeks and weeks. She was becoming very dependent." (5,1,1,12)
iii) LINKING

The third sub-theme, linking, related to volunteers' function of liaising with hospice services and the community. Alerting other team members to situations in which carers required to be linked to different or more specialised support systems was an important monitoring role for volunteers. Liaison with the hospice team, identified other supports that carers' could access. A volunteer described her role in monitoring carers' recovery:

"If I strike any difficulties and if there are any problems I go directly back to the team. I wouldn't take it on myself to do counselling or anything like that. I've got antennae up for any problems and then I report back to the nursing sister and say that this was out of my depth ... and someone else takes over." (5,6,8,3)

Another important liaison activity was informing carers of available supports, such as drop-in-centres and community groups and facilitating their re-integration into the community. In some circumstances volunteers liaised with community networks to find innovative solutions to carers' problems:

"I am visiting a German lady at the moment. She has been having a difficult time, as she has only one son in Israel and that's very difficult for her, as she doesn't know what's going to happen there and she has no other family. Actually I was able to contact a couple of friends from Germany and she was able to talk to them on the phone more easily. She comes to the drop-in centre now." (5,10,13,22)

Volunteers expressed different opinions of the function of drop-in-centres and the usefulness of drop-in-centres to carers. Some volunteers valued the availability of drop-in-centres as a venue for carers to practice social skills and regain confidence in
interacting with others in a supportive environment. This was particularly important for carers who were socially isolated:

"The drop-in-centres are stepping stones for people. They are often at a loss. Even although they may have good family support, they need to get out with people who are experiencing the same thing. It's not an ongoing social thing but really for people to get back into the world and communicate with other people. It's not specifically to discuss bereavement." (5,6,10,1)

Drop-in-centres could also provide a transitional function by encouraging carers to develop community interests:

"There are some people who have been coming here for two years but we feel it's better to encourage them to try other things. For example, one woman enjoyed walking but she said 'I don't enjoy walking any more because I always walked with my husband. 'But we helped her to join a walking club here and then she introduced someone else to the walking club and she goes too. And someone else who is interested in dancing introduced this chap who hadn't been out anywhere for years and so he's going to dancing classes now." (5,10,16,2)

Alternatively other volunteers felt that drop-in-centres could have provided greater opportunities to work through grief and that volunteers involved in drop-in-centres had a role in monitoring carers' progress and communicating with other team members:

"I feel that there should be more follow-up from the drop-in-centre to the person doing the bereavement. I think there should be more structured communication there. I mean, I
have referred a couple of people there who hadn't turned up, and I was a bit disappointed that it wasn't followed-up." (5,8,16,4)

There was general agreement from volunteers in this group that drop-in-centres fulfilled an important function within the bereavement service for some carers enabling them to gain confidence towards reinvesting in community activities as a single person.

iv) DISENGAGEMENT

Disengagement related to the process of finalising bereavement contact with carers. This may occur following the first telephone contact or after a series of bereavement visits. Although volunteers experienced considerable autonomy in their contact and means of support of carers, they also felt that adhering to service guidelines provided safeguards in relation to the frequency of contact and level of involvement expected in the role of volunteer. It was common for volunteers in this group to inform carers on initial contact with them, of the service time frame so that there would be an expectation, on carers' behalf that bereavement visits would not be ongoing. Volunteers' experiences of finalising contact was influenced by whether they had prior knowledge of the family. In cases where the carer was unknown to the volunteer, it was common for telephone contact to be the only means of communication. Connecting and disengagement, therefore, occurred at the initial contact:

"I find with a 'healthy' bereavement, a telephone call is enough, or maybe two telephone calls. With a 'healthy' bereavement you don't always need to have a big input." (5,6,6,17)

When volunteers had been involved with families in the illness phase, they could have problems in finalising contact:
"The volunteer has to be protected as well, otherwise you could get so involved. When you've been with a family for long-term relief care and then go in for bereavement, and the nurses pull out after a while, sometimes the carer is reluctant to let you go. They hold onto you because that is their last tie with everything that's gone on. Sometimes that can be difficult." (5,2,8,7)

When volunteers had difficulty in disengaging from particular carers, they contacted other team members for support and advice. Some volunteers reported that their relationships with carers continued on a friendship basis for many years.

6.7. DISCUSSION - CONNECTING

According to Beigbeder (1991, p. 106), the basic motivation of volunteers is altruistic. They have a personal need to help others and to feel useful and needed. They also want to belong to a group which share the same values. The philosophy and values of hospice care was shared by the group of volunteers interviewed for his study, all of whom had personal experiences of grief and loss, previous involvement in providing human services or previous involvement with receiving hospice services. The common experiences of volunteers and carers related to loss and grief encouraged the adoption of a self-help ideology. It was a common belief of volunteers that their role was facilitative and that the strength of recovery from grief was within bereaved carers themselves. This had the effect of absolving volunteers from personal responsibility in relation to carers' recovery and strengthened volunteers' acceptance of the process of providing bereavement support according to service guidelines.
The role of volunteers within hospice services has been discussed by Cox, (1978); Ajeman and Mount, (1980); Zimmerman, (1981); Kavanagh, (1983); and Mantell and Ell, (1986), all of whom agreed that training of volunteers to assess bereavement risk and the need for counselling and other forms of help for bereaved carers, made a substantial contribution to hospice services. Durlak (1979), cited in Mantell et al (1986, p. 96), supported this view and stated that there is evidence to suggest that within a hospice environment ... 'non-professional helpers are frequently as helpful, and in some cases more effective than professionals." Volunteers described friendly and informal relationships with families who shared intimate life events through the development of supportive relationships. Volunteer participants in this study commonly experienced positive reinforcement of their roles from carers and this significantly contributed to their commitment to continue to give service. The expectations of the service in relation to formal recording and reporting further endorsed that their role was valued and that they had recognition from other hospice team members.

A large body of literature supports the importance of organisational support resources in counteracting job-related sources of stress (Vachon, 1987; Mohl, Denny, Mote and Coldwater, 1982). Volunteers transcriptions consistently referred to the importance of peer support by other team members which not only provided a safeguard for volunteers when difficulties arose in their contact with carers, but also had an important function related to volunteers' enculturation with the service and feelings of value by association. Limitations of their own skills and the recognition of when to refer to more specialist services was an important function of volunteers who considered their monitoring role as highly valuable to the service. Linking carers to other support networks such as drop-in-centres and community organisations was also a role valued by volunteers although not all volunteers perceived that facilitating community involvement was within their
mandate. Volunteers' views about the functions of drop-in-centres were variable. While some volunteers believed that drop-in-centres should provide more structured opportunities for expression of grief, others felt that drop-in-centres provided opportunities for practising unused social skills and had a transitional role in community reintegration for carers.

Problems arose for volunteers when they were unable to follow through on referrals from nurses due to carers' lack of understanding or non-acceptance of volunteers' roles. Providing bereavement support to male carers was also more difficult for a significant number of volunteers in this group. Parkes, (1983), cited in Dayle et al (1993), suggested that men tend to show less overt emotion than women during bereavement and that social pressures to repress or inhibit grief were greater in men. There is a lack of literature available to support sex differences in vulnerability to the health effects of bereavement (Stroebe et al, 1983 cited in May 1988, p. 69) and neither were studies found which examine preferences of bereaved carers in relation to the gender of support workers. This is an area which would benefit from further investigation.

Volunteers from this group consistently discussed particular problems related to carers who had limited English or who had different cultural expressions of grief expectations of bereavement support. As all the volunteers interviewed were from Australian or Anglo-Saxon origin, limited exposure to grief practices of other ethnic groups may have accounted for this. The exploration of culturally relevant bereavement support practices and recruitment of bi-lingual volunteers may be a strategy to overcome language and cultural differences.
The bereavement support experiences of volunteers were dependent on the level of acceptance of carers regarding their involvement and there was a considerable degree of flexibility in relation to frequency and duration of support. Bereavement follow-up by volunteers was consumer driven by carers' perceptions of their need for support. Volunteers consistently discussed the differences with providing bereavement follow-up when they had known the carer in the illness phase and their experiences of 'going in cold'. A highly valued experience from volunteers' perspectives involved following up carers with whom they had been involved. Eight of the ten volunteers interviewed in this group reported that they felt more comfortable contacting carers who were known to them and that this was more likely to result in face-to-face contact and grief work with carers. When carers were not known to volunteers it was more common for carers to reject volunteers' offers to visit. Volunteers, having fulfilled service requirements, however, still felt that they had provided a valued service. Although assumptions cannot be made regarding the need for carers to receive bereavement follow-up services who do not respond to unfamiliar volunteers' offers of support, the consistency with which carers accept support when the volunteer is known and reject support when the volunteer is unknown requires further investigation. If familiarity with the service provider is an important element of bereavement support services, this would have implications for future service development.
Valued 'help activities', their value to volunteers and influences and barriers related to the theme CONNECTING are represented in the following diagram:

**Figure 8.**
6.8. VOLUNTEERS THEME 2

FINDING MEANING

(PERSONAL GROWTH THROUGH HELPING)

The second strongest theme emerging from interviews with volunteers related to the meaning of the volunteer role in their lives. The extensive training provided by hospice was described as a period of personal growth, reflection and opportunity to address personal feelings related to grief and loss.

"The orientation was fantastic. There were only eight of us did it and you learned so much. I found it very interesting and it has been very helpful in my own life." (5,2,3,4)

Volunteers felt enculturated in the service and that their contributions were valued by the organisation. Volunteers described the importance of volunteering in their lives:

"It gives me a feeling of being useful, helping other people, and I really think that is what life's all about as far as I'm concerned. What we can do to help other people is very important to us as a person and giving ourselves to others is important to us." (5,16,5,5)

"I find that I am doing something useful and it's taught me not to be perhaps as selfish as I might otherwise have been, and it's made me thankful for the family that I have." (5,10,25,3)

Validation of the role of volunteer by carers and nurses reinforced the usefulness of the volunteer role and acted as motivating factors in their continuation with the service:
"I'd say it's changed my life completely. It's given me more self confidence and I find it very rewarding, you know. You get these particular ones that are more rewarding than others and to me it's been such a worthwhile thing to do in the community. I hope I'll be able to do it as long as I'm able. It's the people you meet too ... the nurses." (5, 7, 23, 18)

"I had one lady who asked me to visit her a number of times. She was so pleased that someone had been there, and the support helped her along. She said, 'I'll manage, but please come back... don't leave me alone.' After a few visits she said 'I really feel as if I'm turning the corner.' I felt really contented that she was back on the road and able to take an interest in life again." (5, 2, 19, 3)

Volunteers consistently used the words 'privileged' or 'rewarding' to describe their involvement with bereavement follow-up. The intimacy of the relationship which could develop as result of being involved with carers, and the confidential nature of their role contributed to the sense of value volunteers experienced as being part of the service:

"What I have found more than anything, it is trust that develops and then they will tell you things, that you don't put down on the report or anything. You don't reveal a lot of things they tell you because it's between you and them." (5, 8, 14, 25)

"I always feel good because they have been able to tell me their story, and some of the stories are quite intimate. I had a feeling of being accepted and trusted." (5, 9, 19, 7)

Personal gain from volunteering was a shared experience of this group and a strong motivating factor related to their involvement with the service. Volunteers' belief in their
ability to fulfil caring roles developed over time with positive bereavement experiences and this reinforced the value that volunteering had for them:

"I have done it for my own personal gains, because I have a need to help people." (5,8,14,24)

"I have come away feeling that I have achieved something and that it was good for them and good for me." (5,9,3,17)

Personal gain from being involved in a service which provided emotional support through peer networks was also a motivating factor for volunteers:

"It's a feeling of caring that you get from the service. That they care about you too just like all the nurses care about their patients." (5,7,24,1)

Regular and formal appraisal of volunteers allowed them to give and receive feedback on their involvement with bereavement support. This further reinforced their value to the service and enhanced self-esteem.

6.8.1. DISCUSSION - FINDING MEANING

People engage in volunteer activities to fulfil a number of different needs, including attainment of status, sense of affiliation and belonging, opportunity to undergo vocational training, leisure-time diversionary activities, self worth, desire to help others, and personal growth (Naylor, Newell, Marcus, Cherico and Seeland, 1981) cited in (Mantell et al, 1985, p. 90). Abrams, Abrams, Humphrey and Snaith (1986) cited in (Vellekoop-Baldock, 1990, p. 89), believed that reciprocity is essential for voluntary care
to survive and that those who help as well as those who are helped should gain from the experience. Volunteering can also provide people with an identity. Purposive incentives by identification with the role of hospice volunteers was strongly expressed by all members of this group who stated that involvement with hospice had an important role to play in their lives. Personal gains from this role involved recognition by the service, recognition by nurses and carers and recognition and value allotted by the wider community to people involved with hospice care. Volunteers also viewed their association with hospice as a period of learning and personal growth.

Because volunteers give their time freely they are not constrained or diverted by involvement in an organisational hierarchy (Kavanagh 1983, p. 216). The opportunity to offer simple, human companionship and neighbourliness which is essential to the caring community, and in return be compensated by fulfilling a valued role of helper, provided volunteers with opportunities to continue roles which reinforced their personal values and beliefs. Appraisal of volunteers’ performance ensured that volunteers’ capabilities were recognised and that volunteers were accountable to the organisation. Appraisal also provided an opportunity for volunteers to have their opinions heard, and was viewed positively by volunteers who felt a sense of affiliation and valued by the organisation.

According to Dayle et al, (1993, p. 675) volunteers working on hospice home care teams may get to know and befriend families who will share with them thoughts and feelings they will never share with a nurse or doctor. The development of supportive relationships with families was highly valued by this group of volunteers and reinforced their sense of personal efficacy in the role of helper and in the role of hospice volunteer. Although the intrinsic nature of the population served by hospice volunteers was potentially stressful, the autonomous nature of the volunteering role in bereavement
follow-up allowed volunteers to retain control over their own time and activities thus reducing stress and acting as a motivating factor in volunteers' involvement with the service.

Training of volunteers involved experiential training methods and encouraged active participation confronting personal feelings about death and dying. All volunteers in this group felt that training had benefited them and had facilitated a greater development of insight into their own feelings related to loss and grief. Volunteers interviewed did not express any barriers to the development of finding personal meaning in the role of volunteering and all volunteers stated that their lives had been enhanced by involvement with the service. The positive view expressed by this group of volunteers must be related to the context of their continued involvement with the service. Volunteers who had left the service were not interviewed as this was outside the parameters of this study.
Valued 'help activities' their value to volunteers and influences and barriers related to the theme FINDING MEANING are represented in the following diagram:

**Figure 9.**
6.9. LINKING THEMES

The following diagram demonstrates the way that carers', nurses' and volunteers' themes link to form the interactive environment of the service.

![Diagram](image)

Carers' theme 'mutuality' was strongly linked to nurses' theme 'resolving grief' and volunteers' theme 'finding meaning'. The care-giving environment within hospice home care, which was unrestricted by institutional values and beliefs, allowed participants in the bereavement program to develop reciprocity in relationships. In this way carers, nurses and volunteers were able to encourage the expression of feelings related to the mutual experiences of their involvement in the area of loss and grief. This created service relationships which were intimate and interdependent.

Existentialists suggest that the construction of meaning in life is central to the human experience and that life's experiences become more intense when individuals continually remain aware of their mortality (Charmaz, 1980, p.45). It could be suggested that by subjectively confronting the meaning of death, people also subjectively face the meaning of their lives. Carers', nurses' and volunteers' sharing of experiences was characteristic
of a program which had existential relevance for participants in the context of their own lives. Nurses and volunteers chose to work in the area of death, loss and grief, and found meanings in their interactions with carers which fostered personal growth, just as carers developed a sense of belief in their own coping abilities as a result of finding meaning in their personal experiences of loss. The confrontation with death in the day-to-day involvement of nurses and volunteers in bereavement follow-up, encouraged the development of a raised consciousness of nurses' and volunteers' personal mortality. Nurses' resolution of their own grief in the bereavement environment was supported by carers who recognised that nurses shared with them a mutual experience of loss. Creating an environment in which nurses could also express sadness following loss was important for nurses' emotional well-being.

The ability of nurses to recognise their grief and be supported by peers and carers, created an enabling environment in which all participants within the program felt comfortable in meeting their own needs and recognising the needs of others. Nurses' repeated griefs enabled them to cope more sensitively and more confidently with each repeated loss and bereavement. This may also be applied to volunteers whose finding meaning by establishing a feeling of reciprocal trust and esteem with carers in the process of resolving their grief, was the motivating factor for their continued involvement with the service.

The consistent use of the word 'friendship' to describe relationships between carers and nurses, and carers and volunteers, demonstrated the mutual trust which had developed between carers and providers of bereavement support services. This allowed nurses and volunteers to be permitted to share in the grief of carers, become their chosen confidents, and actively support their grieving process.
Continuity of care in hospice bereavement services allowed carers to receive services without major disruptions or abrupt transitions. Continuity also permitted the important bridging of life and death experiences for carers, nurses and volunteers who had been involved in the illness phase. The themes 'continuity' and 'concluding care', described the process whereby the service continued to meet the needs of carers and nurses during the early stages of bereavement. Volunteers' theme 'connecting' related to the themes 'continuity' and 'concluding care' by describing volunteers' involvement in a transitional role, supporting nurses' disengagement by providing continued bereavement support and linking carers with community organisations and activities.

Continued involvement by nurses with bereaved carers met nurses' needs to conclude their care and uphold their values and beliefs regarding the way the service should be provided, and carers needs to resolve their relationship with nurses with whom they had shared a significant and intimate life event. Volunteers' role in connecting with carers and their presence within the program enlarged the environment in which healing could occur. Volunteers connecting with carers allowed volunteers to perform an important linking function by circulating information and communicating with carers, the hospice team and community.

Volunteers' theme 'connecting' also linked closely to carers' theme 'collaboration' and nurses' theme 'building confidence'. The collaborative relationship which developed in the illness phase between carers and nurses to maximise the patient and carer's control in the dying process allowed a sharing of responsibility for the outcomes of care. Mutually supportive and collaborative roles between carers, nurses and volunteers which had been established during the illness phase, when carried through to bereavement, reinforced carers' beliefs in their ability to cope and nurses' and volunteers' sense of competence in
helping. Collaboration was a characteristic of care-giving and empowered both recipients and providers of services by fostering a philosophy of shared responsibility. Open communication and shared decision making was also a characteristic of relationships between carers and volunteers. The opportunity to self-initiate contact which was characteristic of the mode of delivery of the service in the illness phase, was empowering for carers and also empowering for nurses and volunteers by allowing them to disengage from the service whilst providing a safeguard for carers if they had future needs for support.

The knowledge nurses derived from training, experience and prior contact with carers in the illness phase allowed them to confidently evaluate carers' coping abilities. Nurses shared their skills and knowledge with carers and volunteers in the illness phase to ensure maximum care for the patient whilst recognising that carers and volunteers also contributed special skills to the caring environment. Carers, nurses and volunteers continued to be collaborative within the bereavement service. The sharing of knowledge and skills between nurses, volunteers and carers, allowed supports to be instituted for carers in the bereavement environment, combating feelings of loneliness and isolation. The accrued knowledge of nurses and volunteers as a result of their involvement with bereavement also allowed them to make astute judgements regarding carers' bereavement status. Feedback from carers and the utilisation of nurses and volunteers for support during bereavement enhanced the development of confidence of both nurses and volunteers and validated their roles within the service.

All themes shared a common link. The influence of the nature and duration of prior contact between carers and service providers impacted on the delivery of valued help activities and subsequent meaning and value of the service for carers, nurses and
volunteers. The value of continued support during bereavement by familiar service providers from carers' perspectives, and the value of providing services to carers with whom a prior relationship had been established from nurses' and volunteers' perspectives, was persistently voiced by all participants in this study. If no prior relationship exists between carers and service providers involved in a bereavement program, there may be different skills required by people delivering bereavement support services than nurses and volunteers have demonstrated in this study.

6.10. LIMITATIONS OF THE STUDY

The limitations of the study were related to the sample of participants' interviewed. Although participants involved were assumed to be representative of the larger population, the restriction in the numbers who were able to be interviewed in the course of the study will have affected external validity. Ethical considerations precluded randomly selecting newly bereaved carers. The function of nurses as gatekeepers in the selection of this group may have biased the study towards inclusion of carers who viewed the program positively. It must also acknowledged that the emotional state of bereavement itself may also have influenced participants' narratives. Data was collected from carers who were no longer receiving services. Their retrospective accounts of experiences may have affected accuracy. Nurses and volunteers, although randomly selected from service records, were also likely to report positively on their experiences as they were also a vulnerable group in relations to their dependency on the service for employment and self-worth. Despite these limitations, however, negative cases were identified and areas of unmet need proposed.
Although the sample size was small, involving in-depth interviews of thirty consumers and twenty providers of bereavement support, over fifteen hundred pages of data was collected. This allowed content analysis to reach the point of saturation, and persistent patterns and concepts to emerge from the data which could be grouped to form major themes.
CHAPTER 7
ELEMENTS OF A VALUED BEREAVEMENT PROGRAM

The purpose of this chapter is to identify characteristics of a valued bereavement program which have emerged from analysis of the experiences of carers, nurses and volunteers. Valued help activities which relate to major themes will be discussed from the perspectives of carers, nurses and volunteers.

7.1. CARERS' PERSPECTIVES

FAMILIAR NURSE VISITS
Bereavement visits by nurses who had been involved prior to the death were highly valued by carers and allowed opportunities to discuss the illness, and death process. Immediate follow-up by familiar nurses and subsequent visits in the early weeks of bereavement were cited by carers as the most highly valued bereavement support activity. The familiar relationship and sense of shared experience encouraged carers to express their grief and begin their recovery. The return of familiar nurses also allowed reality testing to occur and the continuation of a collaborative relationship which reinforced carers' perceptions of their ability to cope with their loss.

FAMILIAR VOLUNTEER VISITS
Visits by volunteers who had been involved prior to the death were highly valued by carers. The continuation of a familiar and trusting relationship and shared memories of the deceased also encouraged reality testing and the comfortable expression of grief. Visits were more highly valued if more than one visit was undertaken. Information on
other community support networks and practical support with re-establishing social networks were also valued.

TELEPHONE CONTACT BY NURSES AND VOLUNTEERS
Telephone contact with nurses and volunteers, if visits could not be undertaken, were also valued. If the contact was made by nurses and volunteers who had prior contact with carers, this was more highly valued than contact with bereavement support personnel who had no prior involvement.

INTRODUCTION OF VOLUNTEER BY NURSE
When carers required more support than nurses could offer, due to time restraints, volunteer support was valued by carers. The acceptance of volunteers by carers in the role of bereavement support was more likely to be successful if a smooth transition of care from nurse to volunteer occurred. The introduction of the volunteer by the familiar nurse was a positive strategy to achieve acceptance.

FORMAL DISENGAGEMENT BY NURSE AND VOLUNTEER
Carers valued knowing that nurses and volunteers would no longer be providing support. If this was not negotiated with carers and if they were unaware that nurses and volunteers would not be continuing to visit, they remained uncertain regarding their access to services and the availability of support in the future.

SELF - INITIATION OF CONTACT
Carers highly valued the opportunity to self-initiate contact with the service when needed. All carers expressed comfort with initiating contact with the service and this was an important safeguard in their ability to work through their grief. Knowing that help was
available in times of acute grief, even if they did not actually access support, provided a
significant supporting mechanism for carers.

PROVISION OF A CULTURALLY RELEVANT SERVICE
It was important for carers from different cultural backgrounds and carers who had
difficulties in making their needs known as a result of limited English, to receive
bereavement follow-up services which were coherent with their underlying values and
beliefs. Inability to convey feelings and receive support as a result of cultural and
language differences, increased carers' feelings of frustration and social isolation.

OTHER FAMILY MEMBERS SUPPORTED
When other family members were closely involved with the death and the primary carer
was unable to support them due to his/her own grief experiences, the availability of
support for other family members was highly valued. This was particularly relevant
when children had lost a parent.

IMMEDIATE REMOVAL OF MEDICINES AND EQUIPMENT
All carers expressed gratitude for the immediate removal of medicines and equipment
associated with the illness. This allowed memories of the well person to return and
normalised the carer's environment.

SENDING ANNIVERSARY CARDS AND ST. LUKE'S DAY INVITATIONS
All carers interviewed who had received anniversary cards on the anniversary of the
7.2, NURSES' PERSPECTIVES

FOLLOW-UP BEREAVEMENT VISITS TO FAMILIAR CARERS

The most highly valued help activity from nurses' perspectives was the opportunity to engage in follow-up bereavement visits to carers with whom they had been involved in the illness phase. This allowed nurses to fulfil values and beliefs related to service delivery by concluding their care, and also provided opportunities to resolve the grief which nurses experienced as a result of the loss of the patient. Follow-up bereavement visits were described by nurses as important for their emotional well-being and job satisfaction.

TRANSITION OF CARE TO VOLUNTEERS

The availability of volunteers to provide ongoing support to carers, which allowed nurses to reinvest in other families, was highly valued by nurses. The monitoring role played by volunteers and their communication with nurses related to carers needs, supported nurses' disengagement from bereavement support. Nurses were more likely to value volunteers involvement with carers when face-to-face contact had occurred between volunteers and carers.

PEER SUPPORT

Involvement in a service which had informal and formal support networks in times of job stress, was highly valued by nurses. Nurses cited informal peer support and guidance as the most highly valued support mechanism available to them. Working in a supportive team was a source of job satisfaction and fostered continued involvement with the service.
EDUCATION AND TRAINING

Opportunities to be involved in ongoing education and training was highly valued by nurses who generally preferred workshops and discussion as a means of developing skills. The availability of ongoing training at a local level and involving all members of the team was suggested by nurses as a possible future educational strategy.

FLEXIBLE SERVICE GUIDELINES

Flexibility in service delivery to meet the needs of individual carers was viewed positively by nurses. The autonomous nature of home care services allowed bereavement follow-up to be driven by carers' needs. Nurses preferred to use personal judgement in their involvement with carers as opposed to adhering strictly to service guidelines.

7.3. VOLUNTEERS' PERSPECTIVES

ASSOCIATION WITH HOSPICE CARE SERVICE

Volunteers highly valued their association with hospice home care and strongly identified with the hospice philosophy. Opportunities to communicate with other team members and the recognition of having provided a valued service to the organisation was consistently reported by this group as being highly valued. Structured reporting procedures through regular group meetings, written format, and information exchange related to carers' needs were positive recent service developments from volunteers' perspectives. The availability of immediate support from other team members related to carers' or volunteers' problems was a motivating factor for volunteers continuing to be associated with the service.
BEREAVEMENT VISITS
Carers' acceptance of volunteers to provide support during bereavement was highly valued by volunteers. Recognition of having special skills to offer to carers validated volunteers' roles within the service and enhanced their feelings of worth. When volunteers had been involved with carers during the illness phase it was particularly rewarding for them to be involved in bereavement follow-up.

TELEPHONE CONTACT WITH CARERS
Volunteers' involvement with unfamiliar carers, following referral by nurses or bereavement co-ordinators was most often by telephone contact. This was considered satisfying for volunteers in meeting service requirements and also gave carers an opportunity to accept face-to-face bereavement support. When carers preferred to talk at length about their experiences by telephone but did not accept a bereavement visit from volunteers, this was less satisfying from volunteers' perspectives.

EDUCATION AND TRAINING
All volunteers in the group interviewed highly valued the orientation to the service and the training provided. Volunteers considered themselves skilled listeners and facilitators of grief support, and valued the selection procedure in place by the service for volunteers who are interested in the bereavement area. Volunteers felt that they had standards of care to meet and this reinforced their perception of their value to the service. All volunteers reported that involvement with the service, and the training provided, had resulted in personal growth and fulfilment.
CHAPTER 8
CONCLUSION

This chapter will discuss the research objectives and the manner in which they have been met by the study.

8.1. OBJECTIVE 1

To demonstrate the use of a qualitative evaluation method to identify key areas for program development in the context of a bereavement program.

This study adopted a qualitative approach to examine the valued interactions within a bereavement program from the perspectives of program participants. By allowing real-world situations to unfold naturally, without manipulating or controlling variables, the evaluator was open to whatever data emerged from informants. The evaluation outcomes were, therefore, unconstrained by predetermined controls. A phenomenological method of data collection provided thick descriptions of informants' experiences with the program. By a process of face-to-face in-depth interviews, the evaluator had close contact with informants and the program under study. As a result, the evaluator's personal experiences and insights were an important part of the inquiry. An inductive analysis of transcribed narratives identified consistently emerging phenomena within the program which were described as major themes. The interdependencies of interactions and activities related to these major themes were then able to be described.

By being responsive to whatever data emerged from the evaluation process, and validating or negating emerging phenomena as they arose by a process of theoretical sampling, the evaluator strengthened the credibility and validity of the findings. The
implementation of a responsive approach to evaluation and the involvement of multiple informants from different program sites, enhanced the generalisability of findings within the context of the bereavement service. A more controlled study involving structured interviews would have been unlikely to uncover the breadth of information obtained in this phenomenological approach. Thick descriptions of program involvement from participants' perspectives consistently related to commonly valued aspects of program processes across groups of informants. Valuable information for future program development was obtained and presented to the organisation.

8.2. OBJECTIVE 2

To develop a framework for human service evaluation which had as its focus the experiences of participants related to their interactions with the service.

This study adopted a symbolic interactionist framework to evaluate a bereavement program. The conceptual framework was underpinned by an assumption that there were common experiences shared by people receiving and providing services and that such experiences would be perceived by participants either positively or negatively. This approach enabled the researcher to understand and interpret the social reality of the program through the meanings that informants attached to their interactions. The consequences of the interactions determined the value allotted to program experiences by participants within the parameters of their own life styles.

By including consumers and providers of a bereavement program, the evaluator acknowledged the interdependence of both in program outcomes and the existential nature of the interactions between vulnerable groups of people who receive programs and those
who deliver them. The importance of gaining insight into the interactive environment of the program so that the experiences and needs of consumers and providers could be better understood was a necessary strategy for ensuring that the needs of both groups would be considered when program change was planned. This is required if a holistic approach to service delivery is to be ensured.

The framework adopted for this study allowed the underlying assumptions of consistently shared experiences within the program to emerge. This has been demonstrated by linking themes between the three groups of informants by identifying the importance of service relationships related to participants' perspectives of what was valued within the program.

The study demonstrates the great depth of understanding to be gained by focusing on the experiences of participants. The themes identified by consumers and providers can be used by the agency to develop ongoing services that match more closely with the needs expressed. Thus the framework of symbolic interactionism used demonstrates clearly its use as an evaluation tool.

8.3. OBJECTIVE 3

To identify the meanings shared by consumers and providers in a bereavement program related to their experiences with the program

A phenomenological view of human nature assumes that people are capable of reflective thought and not just products of social forces. The construction of meanings in relation to involvement in a bereavement program, was, therefore, an ongoing process developing out of informants' conscious attempts to make sense out of experiences.
The interpretation of the meanings of experiences related to informants' involvement with a bereavement program was undertaken by a comparative analysis of informants' descriptions so that shared meanings could be identified. Accepting the every day language of participants allowed their experiences to be represented in their own terms and according to their own world view. The essential characteristics of a bereavement program from the perspectives of informants were then identified. Raw data, in the form of participants' descriptions, were used to compare and contrast common experiences, identify valued interactions, and barriers to program needs being met. Judgements related to the identification of valued experiences were made by the evaluator on the basis of consistent description by informants.

8.4, OBJECTIVE 4

To identify which interactions within a bereavement program were highly valued by consumers and providers

Analysis of participants' descriptions identified common language used to describe interactions between nurses, bereaved carers and volunteers which were highly valued by them. A significant finding was the dominating influence of service relationships on participants' perspectives of a valued service. The value of the activities and processes of the bereavement program were consistently described as human interactions between program participants rather than task related behaviours.

From analysis of interview data, it was possible to identify valued interactions from the perspectives of each group of participants, examine the similarities between groups, and discuss how they interrelated with each other in the construction of the program. (This is summarised in figures 2 - 10 in Chapter 6). By examining each group separately, insight
could be gained about the experience of the service in relation to the different roles of participants and increase understanding of program experiences from different perspectives. This allowed an holistic interpretation of the program. Elements of a valued bereavement program which required safeguarding in future program planning were then able to be identified. Briefly these elements, from carers' perspectives were: face-to-face support visits and telephone contact from nurses and volunteers who had known the deceased; personal introduction of volunteers by nurses; self-initiation of contact by carers and ongoing availability of support; clear communication between carers and providers regarding the cessation of support visits; culturally relevant bereavement support follow-up; removal of medicines and equipment; commemororative cards and service. From nurses' perspectives, valued elements of service delivery were: follow-up bereavement visits; availability of volunteers to provide ongoing support; emotional support from peers; education and training; flexibility in service delivery guidelines. From volunteers' perspectives valued elements of volunteering were: acknowledgement of a valued role within the service; bereavement support visits and telephone contact with carers; education and training.

8.5. OBJECTIVE 5

To identify influences on, and barriers to, highly valued interactions

Initial random sampling of representative cases of bereaved carers, nurses and volunteers provided data on typical experiences of involvement in a bereavement program. The influence of service relationships as a significant factor on the value of program experiences was established from the analysis of each group of randomly selected informants. Within the random group of bereaved carers there were also people who had limited bereavement follow-up which allowed for comparison. Cultural factors in
service delivery arose from the analysis of interview data from each group from the initial random sample. As barriers to valued interactions arose from the data, further discriminate sampling to verify findings was undertaken. In this way barriers to valued interactions were consistently identified. From carers' perspectives, barriers to valued service interactions were: absence of prior service relationships with the bereavement support provider; the involvement of multiple service providers; uncertainty about the service purpose and the roles of providers; missed contact between carers and providers; cultural and language barriers; premature cessation of support visits; inability to close the relationship between carers and providers; reluctance of carers to value their personal need for support. From nurses' perspectives, barriers to valued service interactions were: time constraints; personal relevance of the bereavement situation; discomfort in the role of bereavement support provider; the process of transitioning support services to volunteers; availability, location and timing of educational workshops. From volunteers' perspectives, barriers to valued service interactions were: absence of a prior relationship with carers; carers non-acceptance of the volunteer role; cultural and language barriers.

In keeping with the ethics underpinning this study, barriers to valued interactions were included as elements of a valued bereavement program in order that relevant strategies could be introduced and safeguarded in future program planning. By identifying areas of unmet need as valued elements of service delivery the evaluation maintained a positive approach whilst identifying gaps in service delivery.

8.6 CONTEXTUAL INFLUENCES

It must be acknowledged that the service milieu of hospice home care, the experiences of people consistently working in the areas of death and grief, and the experiences of people
who were coping with grief, created a unique human service environment for the study. Confronting death and grief had a common existential relevance for those involved, as ultimately people were powerless when confronted by death. This allowed for a service delivery mode which was free of the constraints and power conflicts which so often interfere with the 'human' aspects of human services.

Despite the uniqueness of the service environment, and the inability to generalise findings outside the context of the program under evaluation, the underlying principles of a valued service were clearly demonstrated. The interactions between consumers and providers within a bereavement program which reflected positive service relationships were the most highly valued aspects of the service for both consumers and providers.

The decision to undertake a qualitative approach to the evaluation of a human service program was prompted by a dissatisfaction related to the purpose and outcomes of evaluations in which the researcher had been involved as a provider of services. A secondary objective of this study was, therefore, to explore the possibility that it was indeed possible to implement an investigation into a service which was 'value neutral', operated at a grass roots level, and presented accurate information in a manner which identified the needs of participants within the program in a positive manner. This would allow the service to develop strategies to safeguard valued aspects of the program, which would in turn ensure that unmet needs were addressed. In this way, neither the participants or program would be harmed in the evaluation process and the ethical values of the researcher would be met.
In undertaking a phenomenological approach to the evaluation of a human service program the researcher was quite unprepared for the experiential nature of this research paradigm. A quotation from Marcel (1971, p. 25), is appropriate for reflection at this point:

It is an undeniable fact, that though hard to describe in intelligible terms, that there are some people who reveal themselves as present - that is to say, at our disposal - when we are in pain or in need to confide in someone, while there are other people who do not give us this feeling, however great is their goodwill... the most attentive and most conscientious listener may give me the impression of not being present; he (sic) gives me nothing, he cannot make room for me in himself, whatever the material favours he is prepared to grant me. The truth is, there is a way of giving and another way of listening which is the way of refusing oneself; the material gift, the visible action, do not necessarily witness to presence... presence is something which reveals itself immediately and unmistakably, in a look, a smile, an intonation, or a handshake.

Marcel's notion of 'presence' aptly described the experience of the researcher in undertaking this phenomenological study. The area of bereavement was not initially selected out of an interest in grief and loss. As a result of this research, however, the researcher was confronted with the necessity to address personal issues of grief, loss and mortality, as the result of sharing the experiences of participants. This has proved to be an acutely meaningful and productive experience. The extent to which absorption in the experiences of participants occurred by listening to tapes and reading transcripts during the process of data analysis was unexpected. The emotional energy invested in the research as a result of entering the world of acute grief, initially led to feelings of discomfort and concern related to the ethical issues involved, particularly in terms of bereaved participants' vulnerability as recipients of a service on which they depended at this time. These concerns were dispelled, however, with the realisation that the interview
situation had therapeutic benefits by providing an opportunity for bereaved participants to 'tell their stories.' This reinforced, for them, that death had occurred.

Experiences from interviews with hospice nurses and volunteers provided much insight into the nature of their 'human' capacities to provide help for people who are grieving. Their openness in communicating with the researcher and the rapport which was immediately established, ably demonstrated their skills in 'presencing'.

Extensive fieldwork entries, recorded following each interview provided not only a source of subjective observational data but also allowed for the necessary expression of some of the feelings associated with the research.

The study will conclude with three of the researcher’s journal entries which illustrate the research experience:

(JOURNAL ENTRY, 1/9/93. A newly bereaved widow who had been married for forty-eight years).  
"It was as if time was standing still for her. The house was silent and curtains half-drawn, although it was a sunny September day outside. She had been waiting for me and welcomed me. We had tea. A tray had been set for my arrival. Her cup was only half empty before the overwhelming flood of her grief propelled us both into her urgent personal world. I remained with her."

(JOURNAL ENTRY, 9/11/93. A widower who had lost his second wife seven months previously). "I left the interview with him feeling that I had been, perhaps, his only caller that week. The loss of his second wife from cancer had compounded his grief for
his first wife with whom he had shared most of his life. I felt that it was incongruous that he and his wife had moved into a retirement village when the seriousness of her condition had become known. They had thought that being part of a community might provide company for him when she had gone. Yet he was lonely. The door which was welcomely open when I arrived, remained open when I left. The activity from other units struck me as a sharp contrast to his quiet existence. His open door asked for attention. Was it really a case of no-one noticing, or was it the reality of his grief which prevented others from seeking involvement, perhaps for fear of confronting their own fragile mortality?"

(JOURNAL ENTRY, 23/11/93. A widow who had been bereaved for thirteen months). "I thought of what she had experienced in caring for her husband for over six months and the high physical and emotional demands of his care. She had gradually been able to reinvest her energies in family roles and community activities. Although she had been very tearful during the interview, I could feel her strength and energy for life. It felt good to be in the presence of someone who was recovering from grief. I reflected on some of the newly bereaved I had met in the course of the study and felt optimistic for them."
REFERENCES.


*Standards For Hospice & Palliative Care Provision*, (1994). Australian Association For Hospice & Palliative Care.


APPENDIX 1

5, Belford Road,
City Beach,
Perth, 6015.

The Manager,
Silver Chain Hospice Care Service,
44, Sundercombe St,
Osborne Park, Perth 6017.

Dear Ms. Watts,

Please find enclosed a copy of my intended research proposal for a qualitative evaluation of Silver Chain Hospice Care Bereavement Program which I ask you to submit to the organisation's ethics committee for approval.

Subsequent to approval in principle by your organisation, I will submit the proposal for approval to the committee for the conduct of ethical research at Edith Cowan University. Selection and interview of participants will begin as soon as formal approval by the university is received. I intend to complete data collection by 31/12/93, and complete data analysis by 30/6/94.

As part of the university's requirements with regard to ethical issues in research involving human participants, there are formal guidelines for informed consent which must be made explicit to participants prior to their involvement in the study. It will be necessary to include this information in the organisation's initial contact letter. Perhaps I could meet with you regarding this as soon as a decision has been reached regarding the acceptance of the proposal.

Edith Cowan University also requires higher degree students to present their research proposal at a post-graduate seminar where staff and fellow students can comment on the proposed research. The date suggested for the seminar is April 22nd. and I will require approval from your organisation to use the organisation's name before this date. If this time frame is unsuitable to you, please inform me and I will request a postponement.

Finally, I have found the development of a proposal for a qualitative evaluation of your service extremely satisfying and productive. A qualitative approach has not been undertaken before, therefore, questions treated to the methodology are also required to be included in the research design.

I am confident that, if granted approval, useful information will evolve from the study which will benefit both consumers and providers of the bereavement program and enhance future service development. I look forward to hearing from you, and would be pleased to be contacted if further clarification is necessary on 381 0610 during office hours.

Yours sincerely
Ruth Marquis
APPENDIX 2

Silver Chain Hospice Care Service,
44, Sundercombe Street,
Osborne Park, Perth, 6017.

July 1st. 1993.

Dear Mrs. Smith,

Silver Chain Hospice Care Service is undertaking an evaluation of its bereavement support program, and would like to interview people currently using the service and those who have used it in the past regarding their experiences with bereavement support. Your name has been randomly selected from service records and it is for this reason I am approaching you to become involved in a confidential interview with a researcher who has been approved by this organisation to collect information from clients.

I understand that, for some people, this may be difficult due to the very individual emotions arising from bereavement, and I would certainly not wish to cause any discomfort by this request. If, however, you are willing to be interviewed, your information will be very much appreciated. The reason for this study is to consider areas for future program development so that the needs of bereaved people in Western Australia, for bereavement support, can continue to be addressed.

You can be assured that if you become involved in this study, your information will be treated with the utmost confidence and your name will not be disclosed. Interviews will last approximately one hour, in your home, and at a time convenient to you. You may withdraw from the study at any time.

If you are willing to take part, please return the consent form attached by July 20th. A stamped addressed envelope is enclosed for your reply. On receipt of your consent form, you will be contacted by telephone to arrange an interview.

Thank you for considering this request.

Yours sincerely,

Manager.
Silver Chain Hospice Care Service.

I............................................am willing to be interviewed about Silver Chain Hospice Care Bereavement Program. I understand that any information provided by me will be treated with the utmost confidentiality and that I may withdraw from the study at any time.

Telephone no....................