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**The Design and Evaluation of a
Training Programme for the Home Defibrillator**

Cloan Dolores Harris

**A Thesis
in
The Department
of
Educational Technology**

**Presented in Partial Fulfilment of the Requirements
for the Degree of Master of Arts at
Concordia University
Montreal, Quebec, Canada**

November 16, 1995

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ISBN 0-612-10857-0

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ABSTRACT

The Design and Evaluation of a Training Programme for the Home Placement Defibrillator

Cloan Dolores Harris

This qualitative study made a comprehensive assessment of the Home Placement of Automatic External Defibrillators and their use by the Significant Other of patients with a diagnosis of sudden cardiac death. The study assessed the needs of the patients and their families in relation to learning and current support systems available to them during their participation in the programme.

In addition, using the data gleaned from the key players in the programme, a trainer's guide was developed to complement training /educational materials presently being used. Formative evaluations were conducted during the development of the guide. However, as no new participants joined the programme, no summative evaluation was conducted that could measure the impact of any changes brought about in the programme by the use of the guide.

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude and appreciation to the following people:

Dr. R. Schmid, my advisor for his guidance and patience

Dr. M. Rosengarten for his support

The Cardiologists and Cardiology Fellows who participated in the study

Dr. E. Jacobs for her assistance and kindness

The patients and families who participated and made this study possible, a million thanks.

Chris Hanycz and my colleagues in the CCU for their constant encouragement

Peggy Sangster and Staff Development team especially, Helen, Catherine, Daniel,

Louise, Julie, Franca and Tina for their support and assistance

Anne-Brown, Sharon Hyman, France Bourgoin and Lois Hollingsworth for their support

Most of all, Mom, Uncle Ralph, Aunt Velda and my family for EVERYTHING.

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CHAPTER ONE

INTRODUCTION

The last twenty years have seen tremendous advances in the medical and scientific fields due to high technology. Among the most innovative measures in medicine, has been the use of the Automatic External Defibrillator (AED) by laypersons to treat victims of sudden cardiac death occurring in the home. Sudden cardiac death often occurs from lethal forms of cardiac dysrhythmias such as ventricular fibrillation (VF) and pulseless ventricular tachycardia (VT). Effective treatment of either condition depends on definitive care such as early electrical defibrillation and cardiopulmonary resuscitation (CPR). Needless to say a person's chances of survival are greatly reduced if such an event occurs outside the hospital setting.

While more and more non-medical personnel are being certified in CPR, this technique alone is insufficient for the restoration of life to the above victims. Even if life is sustained, neurological status is not intact (Cummins, Eisenberg, Litwin, Graves, Hearne & Halstrom, 1987). Early defibrillation, then, is the key. Factors that have limited the use of early defibrillation were the need for equipment to be used by paraprofessionals such as emergency responders and the availability of such equipment on the scene.

The advent of the AED has changed all this. The AED is a fully automated device with computer circuitry programmed to detect such dysrhythmias as VF and VT and deliver countershocks to return the heart's electrical activity to its dominant normal rhythm. Consequently, this device has opened the possibility to train non-medical/lay persons to provide defibrillation. Because it is considered a medically designated act, the technique was restricted to a designated group of people trained in both the procedure and rhythm identification and management.

Since most out of hospital episodes of VT/VF occur in patients' homes, family members or significant others are most likely to witness the event. This group could, therefore, be included as potential AED operators if trained as first responders (like nurses, ambulance and emergency medical technicians).

According to Mattlin (1987), home defibrillators will be available by physician prescription only. "The main candidates for prescriptions, according to Andersen, are survivors of out-of-hospital cardiac arrest who have approximately a 30% chance of rearrest during the first year and patients with recognized cardiac arrhythmias who have survived a myocardial infarction or heart attack and who perhaps have a 6% to 10% chance of repeat attack in the first year" (p. 63). In essence, home placement of the AED can be beneficial to a selected group of cardiac patients.

The Montreal General Hospital in 1986 pioneered a program to address the needs of this selected group of patients. Under the Directorship of Dr. M. Rosengarten, a

cardiologist and professor within the McGill Health Science Centre, the programme was initiated and today stands as the only one of its kind in Canada. To date there have been ten families who have participated in the programme.

The purpose of the present study is to make a comprehensive assessment of the program to see how to best meet the needs of the patients and families. The present shifts in health care delivery systems from the acute care setting to a more community-based environment necessitates educational preparation for all participants. To effectively assume their changing roles, both medicine and lay persons must know what the expectations are. In addition, the attitudes held by both groups may also need to change to ensure that any new system is efficient and appropriately meets the intended needs. The investigator will use data analyses from the needs assessment to reconstruct teaching materials and protocols (where appropriate) to optimize learning/teaching processes as well as highlight what resources are available to the families.

CHAPTER TWO

LITERATURE REVIEW

Survival from out-of-hospital cardiac arrest caused by ventricular fibrillation or pulseless ventricular tachycardia is determined to a large extent by the length of time from collapse to definitive care with electrical defibrillation (Eisenberg, Bergner & Hallstrom, 1980).

The recent introduction of the Automatic External Defibrillator promised to decrease the amount of time required to initiate defibrillation. The AED gives the potential for diagnosis and treatment of fatal arrhythmias to non-medical bystanders or family members (Jacobs, 1986). The device requires minimal training to operate. AEDs are classified as either fully automated or semi-automated. Once attached and turned on, the fully automated AED assesses the rhythm, charges the capacitors and delivers counter shocks as long as the rhythm remains VF or pulseless VT or until the device is switched off. Semi-automated or shock advisory AEDs require action by the operator, guided by messages displayed on the liquid-crystal screen; a final step is required in which the operator is "advised" to press the shock button when the AED determines that the patient is in VF (Michael, 1993). These devices approved by the Drug and Food Administration in the 1980's are being used by EMTs and more recently

by trained lay personnel and family members. They have, according to Mattlin (1987) signalled "a new and better era of cardiological care" (p.60).

Defibrillators, until the 1960's were found only in hospitals. However, with 375,000 Americans a year at risk for sudden cardiac death, two-thirds of which occur out-of-hospital, the use of AED outside this setting is warranted (Home Defibrillation Study, 1986, Grant Number HS 04894). "Studies conducted in both rural and urban settings have consistently demonstrated that victims of out-of-hospital cardiac arrest were more likely to be resuscitated and discharged alive from the hospital when they received early defibrillation from emergency medical technicians who used AEDs at the arrest scene" (Michael, 1993, p.2).

However, emergency technicians and emergency medical systems do not and cannot always respond fast enough. States W. Douglas Weaver, M.D. a cardiologist and director of the coronary care unit at Harborview Medical Centre in Seattle, "There are many communities in which paramedics and ambulances are not a viable solution". This statement is applicable to situations that also exist within Canada and notably Montreal where the investigator conducted this study. Home defibrillators could improve the survival odds because those who receive defibrillation within the first three minutes of onset of VF or pulseless VT have as much as a 70% chance of surviving. The longer the delay in initiating defibrillation the lower the efficacy of the technique. After 14 minutes the chances of recovery drop to 28% (Mattlin, 1987). Performing CPR was the

only resort available to the lay person/SO until advanced life support arrived. Weaver states that difference between home defibrillators and devices of the past is that now medically unskilled people can do more than just CPR.

Stults, Brown and Kerber (1986) reported their findings on a study carried out to determine AED as an effective alternative to manual defibrillation for the management of out-of-hospital cardiac arrest in rural communities served by minimally trained ambulance technicians. According to the investigators, the initial clinical trial reaffirmed the importance of early defibrillation in improving out-of-hospital cardiac arrest. It also showed that hospital discharge rates in both the AED and manual defibrillation were considerably better than those reported for communities with basic life support alone.

Moore, Eisenberg, Andresen, Cummins, Halstrom and Litwin (1986) conducted a feasibility study of patients who had survived an episode of sudden cardiac death due to VF. The study was to determine who would be potential candidates for AEDs and who would accept having such a device in the home. All survivors of VF in King County, Washington during 1984 were screened for possible enrolment in the study. Of 95 survivors of out-of-hospital VF, 63 (66%) were eligible. Of 47 patients approached, 38 (81%) agreed to participate in the study. To be considered patients had to meet the specific criteria listed:- must return home after discharge, reside with an adult significant other who was physically and mentally capable of learning the use of an AED and had their physician's approval as being medically appropriate for the study. The researchers'

findings indicated that about half (the product of the eligibility rate and acceptance rate equalled 53%) of VF survivors could potentially use AEDs. Exclusion of the other half rested on such circumstances as patients/and spousal refusal for a variety of reasons, e.g., religious beliefs, poor health of the candidate making resuscitation efforts futile or no expressed reason.

Cummins et al. (1987) looked at AED used by emergency medical technicians compared to standard defibrillators used by EMTs. Findings suggested that AEDs are comparable with standard defibrillators and should be considered an acceptable alternative. The advantages by these researchers for users of AEDs when compared with users of standard defibrillators are:- consistent rhythm interpretation, less variability in performance, a shorter time for knowledge acquisition and less expense for both the initial training and ongoing skill maintenance. They concluded that "such devices can make early defibrillation available for a much larger portion of the population. They are a major innovation for the pre-hospital care of the cardiac arrest patients" (p. 1605). This has prompted the American Heart Association to incorporate the use of AEDs in their "chain of survival" in the 1993 standards and protocols for the treatment of VF in Advanced Cardiac Life Support. The chain is summarized as "Early Access, Early CPR, Early Defibrillation, Early Advanced life Care." (Michael, 1993). An approach which provides the best understanding of the treatment of sudden cardiac death.

Data collected over the past 25 years by EMS have invariably shown that early defibrillation is the most effective intervention for victims who suffered sudden cardiac death due to VF or VT (Dimmitt & Griffiths 1992). According to these authors, "in many parts of the country AEDs are being made available to more potential first responders (such as police officers, fire fighters and families of home health care patients at risk for cardiac arrest) and are being placed in public areas where cardiac arrest may occur" (p. 60). Coleman (1992) substantiates this practice by arguing that "perhaps most important, family members have demonstrated that they are able to operate an AED when it counts - during real emergencies at home. Loved ones who went into cardiac arrest have been successfully defibrillated" (p. 57). The new trend is the use of hospital technology in pre-hospital care, technology that is being placed in the hands of paramedics, EMTs and laypersons. As a consequence, many issues and challenges are arising that are impacting on the medical, legal and social systems. Jacobs (1986) in an editorial published in the *Annals of Emergency Medicine* likened the use of AEDs to that of fire detection and prevention in our society. He argued that while smoke detectors and fire alarms have not decreased the incidence of fires, they have decreased loss of life, frequency of severe burns as well as decreased property damage by early detection. In essence, society has benefited through preservation of life/or maintenance of productivity that could be lost through severe burns, lower property insurance costs and fewer medical expenses. Also there is a reduction in the need for large fire fighting

forces and capital cost of housefires and equipment, as building codes are now better controlled. A similar cost benefit analysis for AEDs is possible. This would quantify the potential number of lives saved by the device, the number of man years retained by society and the productivity of those years. A significant factor would be the decision as to where the devices were placed. Jacobs further argued that placement in old age homes would certainly show an increase in the number of VF events. However, the quality and productivity of lives saved in these institutions would differ remarkably from those saved if the devices were placed in the executive suites of corporate America. The question then is at what cost would global implementation of AEDs like fire extinguishers entail? Or, is this analogy fitting when the medical, legal and psycho-social implications of the two are examined and compared?

Cost

According to Dr. Jacobs, AEDs are here to stay and they have the potential to save lives. Three hundred and fifty thousand Americans are at risk for sudden cardiac death yearly (Canadians are estimated at a third of this number) and almost a quarter of the arrests occur outside the hospital (Dimmitt & Griffiths, 1992). Strategic placement of a simple device, AEDs - like the fire extinguisher, coupled with widespread training of the public in its use, could make a difference in life or death for this high risk group but at what cost? Each unit sells for \$7,000 to \$13,000 U.S. excluding such services of quality control, maintenance and repairs. Not to mention training of millions of people

in its use but, also educating them to adapt lifestyles and make changes that would ensure healthier practices that reduce the risk of heart disease. The spinoff from the introduction of fire extinguishers was an increased safety in building codes, an emergency medical service and reduction in lives lost to fire and disfigurement. For AEDs it would be shared governance between the layperson and medicine with the former taking on more responsibility and accountability for such areas as diet, exercise, stress management etc. The salvaging of lives through direct use of the device especially on those struck down in the prime of their careers could mean incalculable benefits to society through their continued contributions both financially and socially. Who would take on the responsibility of educating and training the public and how such programmes would be conducted are still questions to be answered.

Medicine has over the years delegated some of its acts to professionals and para-professionals it deemed qualified to carry out such tasks. Defibrillation is a medical act, delegating and relegating such duties as diagnosing and treating of rhythms disturbances as seen with victims of SCD could be interpreted as abdication of duty on the part of medicine. Should errors occur that are fatal or detrimental to the recipient during an intervention who will take the blame or will there be blame? The good samaritan act which exists in North America relieves one of blame unless the intent to cause bodily harm is established. The use of this new technology may require revisiting the criminal code to offset legal chaos that could result from lawsuits following such an intervention.

Will this new technology enhance or diminish doctor/patient relationship and trust? Better yet, can this be seen as a trend in modern medicine to embrace and practise the concept of empowerment for laypersons (Jacobs, 1986).

These are but some of the issues raised in the 1986 editorial of the *Annals of Emergency Medicine* by Dr. Jacobs and are still relevant and vital in the application and development of this programme. The investigator will address these issues using a system framework to examine each in its entirety. A system' framework allows the researcher/investigator to examine the existing structures, make identification of any problems, justification, reconstruction and implementation of any programme (Kaufman, 1968, 1970, 1972, 1988). It assumes very little about how things are currently being done and examines the inputs, processes, outputs and the extent of interaction with the environment, equating means to the processes and ends to the results (Kaufman, 1979).

The "hallmark" of this approach, according to Kaufman (1988) is to include tools and concepts together with the rationale that identify human and organizational needs and their associated problems before solutions are identified and selected. This approach also includes the positive societal impact on educational planning. "It looks to identify and deliver a better tomorrow, not just make today's efforts and approaches more efficient" (p. 21).

Peter Senge (1990) also advocates system thinking in his book "The Fifth Discipline". Such thinking, he argues allows not only individuals but organizations to

harness the potential of the entire system. Through shared vision or "learning organizations" the system maximizes its growth both effectively and efficiently in the long run. This shared responsibility in the case of those at risk for SCD could prove beneficial and cost effective to both the victims and society at large.

Objectives

The objective of this study was two-fold: to make an assessment of the current home defibrillators programme and then to restructure resources and educational materials based on data analysis findings to ensure optimum use by clients and families. Specifically, in the first phase, I conducted a needs assessment with key players in the programme, i.e., the programme director, past participants (clients paired with significant other), subject matter experts - cardiologists and cardiology fellows in the McGill system. In the second phase, I restructured the learning/educational materials and protocols currently in use to form a learning and resource guide to be piloted on an emerging client and SO. In this phase an assessment was made of three end points:-

1. Assessing ability of SO to learn and retain skills and knowledge of the AED.
2. Assessing the psycho-social effects of AED home placement.
3. Assessing how easy resource/teaching materials are to understand and use.

CHAPTER THREE

METHODOLOGY - PHASE 1

Design and Subjects

This qualitative study focused on educating clients and their significant others (Sos) in the use and implications of the Automatic External Defibrillator in the home. The study was conducted in three phases using a systems approach. Phase I was a needs assessment or front end analysis conducted with the key players in the programme as well as other professionals whose opinions and ideas were relevant in assessing the problem. Phase II was the designing of a trainer's guide based on the data gleaned from Phase I. It also included an evaluation of existing instruction materials presently being used which that could and might be incorporated into the guide with little or no modification. The first two phases were completed by the investigator. Phase III, however, was incomplete because no new participants emerged during the time of the study. A general evaluation of the programme was conducted but no formative was done.

Kaufman (1987) defines a systems approach as a generic problem-solving process which not only allows for problem identification, but also problem resolution. The holistic concerns embodied in this model starts with a needs assessment and moves

systematically from "what is" to "what should be". The model advocates examining both the external and internal needs at the onset, so that a comprehensive view of the problem is ascertained. This approach was necessary for this study so that appropriate recommendations and interventions could be made.

The subjects in the study were clients (past and present) whose diagnosis was sudden cardiac death and who met the specified criteria for home placement of AEDs. These clients were paired with a SO whose role was to operate the device in case of such an event.

The group constituted participants from the programme's inception to September, 1994. The small number generated over the programme's lifespan necessitated that the investigator aimed for the group in its entirety or as close to full participation as possible. Hopefully then, the data reflect the perceived and real needs, concerns and or problems surrounding the problem.

The investigator initially met with the programme director to discuss the feasibility of such a study and the idea was well received. A second in depth interview was conducted two weeks later to explore the various facets of the programme including its inception and maintenance, and to look at the value/benefits such a study could bring to the programme.

Again, there was positive feedback from the director who assured support for the endeavour. He was consequently instrumental in enlisting his patients' participation.

The investigator phoned the director's secretary giving full explanations and details as to what the project entailed. All patients in the programme were initially contacted by the secretary to solicit participation. All nine patients agreed and their names and phone numbers were subsequently released to the investigator. One patient was eliminated from the study due to the fact that his significant other had pre-deceased him and he had donated his machine to the programme. Since the study involved matched pairs, data from this source would have been incomplete. To date, there have been a total of ten patients in the programme, one of whom died of an unrelated problem.

An essential step of any educational endeavour requires a front-end analysis or needs assessment (Harless, 1975; Kaufman, 1987; Rossett, 1987). A needs assessment examines what is presently being done - the actuals - and identifies any existing gaps so that changes can be made to achieve the desired outcomes/benefits - the optimals. A needs assessment was conducted with the following key players -the director of the home placement defibrillator programme, past and present participants and their SOs, two staff cardiologists and three cardiology fellows. Input from the two latter groups of experts assisted in validating the information collected from the other key players (Tesolowski, Newton & Cureton, 1988).

Interviewing Procedure

Programme Director

The actual first step in the interviewing process took place with the programme director. Following a brief discussion with him on AEDs, a planned session was held in his office (see Appendix F). This session lasted one and a half hours and explored all facets of the programme i.e. institution, development, progress and future plans the director envisioned. This unique programme had set a medical precedent in Canada. Survivors of sudden cardiac death (SCD) were being offered an adjunct to standard therapy - home placement of the AED. Technological advances had now enabled a lay person to use skills once reserved for the medically trained in clinical settings. To learn more about the programme and its functions, emphasis was placed on demographic data such as criteria for patient selection i.e. diagnosis, age, social status, support systems, level of education and economics. The investigator at this time asked the director if he had any objections or reservations about having his patients participate in the study: would he be willing to bring it to their attention before the investigator attempted any contact.

The content of the semi-structured interview that followed reflect a review of the literature, past studies conducted, current trends and projected use and need of the AED. Among the questions posed to the director were: how and why was the programme

started and what criteria are used for patient selection. Of special interest to the investigator was the preparation of the family having the device and the kinds of instruction/training in its use the SO received. Other questions for consideration were:

What is the cost?

Who pays?

What resources are available to the family and how long is the device kept? (See Appendix A for the complete interview).

Stults et al. (1986), Moore et al. (1987), Andersen (1987) and Mattlin (1987) have all addressed the issue of sudden cardiac death and the role of non-medical personnel providing appropriate care by using AEDs. These researchers have also looked at the instructional preparation of the AED user and their retention of the skills. More recently Dummitt and Griffiths (1992), Michal (1993) and Angelini and Boecklen (1994) all examined the role of responders in the pre-hospital setting. They recorded an increased use of AED for SCD - especially by such non-trained personnel as EMTs, policemen and fire-fighters. The American Medical Association has recommended in its latest guidelines for Advanced Life Support (1992) that AEDs be part of the equipment for this team of responders including ambulance technicians.

The questions developed for the interview considered areas of concern highlighted in the literature as well as addressed the differences inherent in the medical systems of United States and Canada. The data which emerged from the interview was consistent

with that found in the literature. The director was able to identify a specific target group which could benefit from the AED. He demonstrated that lay persons were indeed capable of and willing to learn instructions in the use of medical equipment. His group now consists of eight families. He is also attempting to show the role medicine is playing in empowering the public in decision-making processes and taking responsibility for their health and well being when appropriate education/training and effective guidance are provided.

The director was supportive of the effort and the necessary details were provided to the secretary for the participants information. The information given was as follows, the investigator is a nurse who works with cardiac patients as well as being an educator in the hospital. To fulfil requirements for a master's degree she wanted to conduct a study of the use of AEDs in the home. This would involve both the patient and SO being interviewed on four general areas: their knowledge of the cardiac problem, training i.e. the AED, problems/concerns encountered and recommendations to those involved in such a programme. Participation was voluntary and interviews would last 15-20 minutes. To ensure patients that confidentiality would not be breached, the patient's names or initials would never appear in print. The investigator neither required nor would have access to their medical files during the project. All information to be ascertained would come directly from them.

After making the initial contact, the secretary provided the investigator with a list of names and phone numbers of the participants. All the patients had agreed to be interviewed. The investigator can assume that the director was instrumental in enlisting the patient's co-operation. The investigator has worked closely with the director over the past fifteen years and has built up an amicable rapport with him.

Other Professionals

To ensure that a broad perspective of the problems and concerns about the use of AEDs was obtained, the investigator also interviewed two groups of professionals closely linked with the cardiac patient. These groups consisted of two staff cardiologists and three cardiology fellows. It was hoped that they would contribute to and/or substantiate the information gathered from other sources. In essence, were the views, ideas and issues expressed by these groups the same identified by the director and in the literature. If no, how and why did they differ. The interviews also assisted the investigator to formulate questions to ask the patient and SO based on some of the issues raised.

The interviews with both groups were unstructured. Questions to them were directed at their knowledge and use of AEDs in general and specifically to the programme at the MGH. For example, under what circumstances would they, as practising or potential cardiologists advocate the use of AEDs and why? What were some of the concerns and issues they had as medical practitioners regarding use of the device in the home or by non-medical personnel.

These informal interviews took place in the investigator's office which is located directly across from the Coronary Care Unit. Interviews were scheduled on an opportunistic basis. During a routine or lull in the unit, the investigator approached an individual and asked if he/she was willing to participate in a ten minute interview in regards to AEDs. There was never reluctance shown by any member, rather great curiosity about the purpose of the study. An additional reason for including cardiology fellows was to determine how they, as future cardiologists might incorporate this new technology into their practice. Again, we discussed what roles they might play in the training and education of the populace towards lifestyle changes with regards to prudent heart living should their patients be in an AED home placement programme.

Responses varied as to knowledge of the MGH programme (See Results section). There was consensus that the trend is towards the increased use of AEDs by particular groups of non-medical personnel. Potential users identified were again policemen, fire-fighters, EMTs. No one predicted a significant increase in the home placement programme. Reasons cited for this were, expansion of such a programme could entail considerable cost which present medical and social services could not specifically undertake. Since the programme is directed at a certain group, meeting all the requirements may still only be achieved by small numbers. Areas where increased placement might be seen are sports facilities and at large public gatherings where non-medical personnel may be the users, e.g. fire-fighters, policemen.

Issues raised pertaining to the programme were the preparation of the patient and family having the device. Of special concern to the investigator was the training of the SO and the psychological effects experienced by such persons should their intervention with the device fail. The question of doctor patient relationship is another issue. An interesting question raised by both groups was who would be ultimately responsible for a generalised instituted public programme i.e., training, maintenance and accountability.

The two staff cardiologists, one female and one male, have been practising three years and fifteen years respectively. All cardiology fellows were males -- two are completing their fellowship and one is in midcycle. Both cardiologists and fellows are part of the McGill University Health Sciences Programmes.

Patient and Significant Other

The programme of home placement of AEDs was instituted at the MGH in 1986. It still remains the only institution in Canada with such a service. All clients, past, present (and emerging) were solicited and agreed to participate in the study totalling eight matched pairs. The primary concerns facing this investigator focused on the training in the use of the device and the educational needs to be met that would facilitate a family's adjustment to this change. Questions facing this investigator were:

- Are other skills needed to complement the use of the AED, e.g. CPR training?

- What resource systems are in place to assist the patient and family who have an AED in the home?
- Would the family benefit from participating in a support group?
- Is there follow-up after the initial instruction in the use of the AED and at what time is this needed?

In addition, there were some secondary questions which were more medically oriented but which nonetheless could be raised during the course of the investigation:

- Are selection criteria in the programme too stringent?
- How is the programme advertised i.e., how are patients and families made aware of such a programme that might help survivors of SCD?
- What role will AEDs play in the future in non-clinical settings?
- Are other more effective methods of treatment presently being used? If yes, what are they and how do they compare with the AED?

The interviews with the patient and SO were largely conducted during the evening except in one case when it was done in the morning. The investigator contacted the participants, identified herself and again explained the nature of the call. This was to clarify/ensure both parties were in agreement and provide the participants with the opportunity to ask questions regarding the study or change their minds if they so desired. The investigator thanked the participants for their assistance before starting the interviews.

Each interview lasted from 15 minutes to half an hour. Either the patient or SO was interviewed first. While the four areas of concern, i.e., knowledge, training, problems/concerns and recommendations were addressed specifically, the interviewer allowed for free-flow of comments. This free-flow method accounted for the range in time and gave the investigator better or further insight into particular needs/concerns/feelings and attitudes the individuals had regarding the experience.

Sample

The patients and SOs who made up the population in this study varied in their socio-demographic traits. (See Table 1 and 11). The age range of the participants was from 26 to 79 years. This takes into account both patients and significant others, male or female. It can safely be assumed that physical abilities differ greatly due to this age discrepancy. Participants came from different socio-economic backgrounds and cited a variety of occupations. These include the homemaker, the retired engineer, university professors, computer analysts, artists and a business owner. The group, therefore, demonstrates diversity in both educational preparation and attainment. As previously stated, one patient from the programme had died accidentally. In another instance, the SO had predeceased the patient. This then makes eight families currently involved in the programme.

Table 1**Biographical Data**

Patient	Age	Sex	Occupation
1	68	F	Home maker
2	79	M	Retired
3	26	F	Graphic artist
4	55	M	Business man
5	61	M	Retired
6	33	F	Clerk
7	54	M	Professor
8	39	M	Surveyor

M = Male

F = Female

Table II**Biographical Data**

Significant Other	Age	Sex	Occupation
1	70	M	Retired
2	75	F	Homemaker
3	28	M	Computer Analyst
4	52	F	Teacher
5	50	F	Homemaker
6	36	M	Dye and Toolmaker
7	50	F	Professor
8	36	F	Business Woman

M = Male

F = Female

CHAPTER FOUR

RESULTS AND DISCUSSION - PHASE 1

Person Interviewed: Director of Programme

Duration: One hour

Interview with the Director of the Home Placement Programme Of the Automatic External Defibrillator (AED)

The central themes of the interview are:

- Initiation of the programme at the Montreal General Hospital (MGH) for survivors of sudden cardiac death (SCD).
- The criteria for patient selection
- The training and education of the SO/family surrounding the use of the AED and consequent need for lifestyle changes
- The responsibility and accountability of the key players
- Future trends envisaged for the use of AEDs

(See Appendix A).

Director of Home Placement Programme of AED's

The focus of this interview with the director was multifaceted. Five broad categories or questions were developed to gather general information about the

programme. Areas covered were the initiation and education provided for the patient and family; and the roles and responsibilities of the key players and future trends in the application of this form of technology. In addition, the investigator hoped to acquire a better perspective of the problem to guide in the development of education and training materials based on identified needs. Needs that could be appropriately and effectively be met through training and education.

Initiation

Question 1: What prompted you to institute this programme at the MGH?

The investigator wanted to determine the need for the programme from a medical perspective. What demands were being placed on the medical system for this type of service and what kind of benefits were to be derived by such recipients and society at large.

The director's reply was it could save lives. As an electrophysiologist as well as a cardiologist, the director was consulted to evaluate and treat patients with rhythm disturbances including survivors of SCD. He would make recommendations for tremendous adjunct to standard therapy. He regarded it as an additional safeguard that could benefit a specific group of patients. He also stressed that it was one of the pioneer programmes in North America. He, therefore, did not have a great deal of data to draw upon at this time. Other centres in the U.S. were also conducting the

same or similar types of programmes and investigations on the uses of AEDs.

Benefits to the patient were the timely utilisation of the AED to save lives and to offset the myriad of complications that can arise as a consequence of prolonged lack of oxygen to vital organs. Training the SO/family members to recognise SCD and act appropriately could influence the outcome of the survivors. Also, timely intervention can offset some of the complications which result in lengthy hospitalisations and rehabilitations which translate into increased cost for both the patient and the medical system.

Question 2: What is the cost of an AED? Who pays?

Cost benefit analysis is/should be part of any new system's endeavour. The investigator examined cost from the patient/recipient perspective as well as the social and medical perspectives. Cost to the patient may mean being able to purchase the device. It could mean cost in terms of quality of life post an arrest event; earning power of the individual if not retired and family circumstances; functioning independently and being a contributing member of society. From a medical and social view point, the cost was assessed for long term benefits. Through early intervention with the AED, the length of hospital stay alone for survivors may be reduced. In essence it is cost effective for all concerned.

According to the director, an AED costs \$7.000 to \$10.000 Canadian. Some recipients have been fortunate to have the device covered by their medical insurance.

In instances where the candidate requires a device but has no insurance, the director provides it until it is no longer needed. In Canada, the device is not covered through Medicare.

Question 3: What is the present status of the programme?

The investigator wanted to learn what demands were being placed on the system and what/if any difficulties were being encountered in meeting the needs of the group. For example, were there more patients needing AEDs than were available devices? If yes, how was this dealt with.

At the time of the interview there were six patients with the AED in the home. There was no specific time of year or age group that influenced when a patient could be diagnosed with a condition requiring this form of adjunct therapy. It simply happens.

Question 4: How long has the programme been in existence?

Here the investigator is looking at the demands being placed on the service and the need for probable expansion. Increased demands could result in more and different needs being identified requiring a variety of resources that may or may not be in place.

The programme at the MGH has been in existence for six years. The low number of patients has not, however, removed the need for its continuance according to the director.

Criteria

Question 5: What are the criteria used for patient selection?

This question examines how patients are chosen for the programme. The investigator expects to find consistencies as to diagnoses, availability of SOs , willingness and commitment on the part of the key players. However, are there other factors that would surface to explain the relative low number of participants over this six year period? In short, are the selection criteria too stringent?

As per the director, there is a specific group of patients who can benefit from this form of adjunct therapy. Firstly, the usual diagnosis is SCD secondary to ventricular tachycardia (VT) or ventricular fibrillation (VF). Often these patients have survived an episode of SCD and may have a reoccurrence. They are patients who are not expected to arrest but may.

Secondly, there must be a SO who resides with or is readily accessible to the patient. This means that someone without family or close friends to take on the role of SO would not be considered. Thirdly, the SO must be capable of following the necessary steps to operate the device. The person must have no physical or mental limitations that would impede performance. There must be consensus between patient and SO about the undertaking. The pair must also understand the responsibilities of the SO and express their concerns and fears so these could be

addressed as part of the preparation. These are the basic requirements. The age of the patient is not a contraindication . The age of the participants in the programme is scattered across the continuum. The end point is that the patient can benefit from this therapy. The quality of the patient's life and functional status are more important than the age.

Question 6: What category of the patients gets/has the device?

The investigator sought to correlate these findings with those identified in the literature. If there were variances, what were they and how did they effect the training/educational needs and preparation of the participants? The literature showed the group of patients to benefit were survivors of SCD due to VT or VF .

The director confirmed these diagnoses cited in the literature. The patients presently using AEDs are those with a diagnosis of VT/VF.

Training/Education

Question 7: What do you expect patients and SOs to know about their cardiac problem?

The answer to this question should provide the investigator with information regarding the participants general understanding of the patients specific cardiac problem. The SO should also be able to describe signs and symptoms of SCD. An important factor here would be to learn how health education is addressed. What are the roles and responsibilities assigned or assumed by the key players? In short, is

prudent heart living incorporated into the belief system/expectations of the cardiac patient and family?

The participant should understand that in the instance of SCD, the heart is beating abnormally. There are different factors that can trigger this problem like an imbalance in electrolytes. Regardless of the precipitating factor the end result is the same. The heart is unable to send blood to the rest of the body, including the brain. The person will then lose consciousness and stop breathing. No pulse is felt on this person. The quicker this abnormality is stopped and the heart returned to its normal pattern, the greater/better the chances of survival for the person. This is where the SO plays a vital role by intervening with the AED. The SO must be taught how to recognise these life threatening signs and symptoms and respond appropriately.

In addition to being taught how to use the AED, emphasis is placed on adjusting to and making lifestyle changes. Patients are advised and encouraged to stop smoking, examine their eating and dietary habits, resolve or minimise family and work-related stress. There must also be ongoing, honest communication among family members.

Question 8: Would you explain the steps or details of a training session with the AED?

Guiding this question is the investigator's concern for the instructional processes used during training. The investigator expects to see the basic principles of

instructional design being followed from an adult perspective. Instructions presented should reflect relevant information based on assessed needs of the learner.

Instructions should be structured so that the information dispensed is congruent with the learner's ability to comprehend. In addition, there should be immediate opportunity for hands-on practice which grounds the adult learner in both the theoretical constructs and practicalities.

The sessions are individualised to suit the needs of the SO. The basic steps to follow in using the machine are simple. The machine with a simulator is used to demonstrate two things. Firstly, it addresses how the AED actually works. All the salient features required for operating the device are explained. How to open the device to activate the messages on the screen and how to follow the instructions are demonstrated. Attachment of the patient to the AED are all part of the learning process. The second important aspect of the session is to show with the simulator, the built-in safety features of the AED. The device will not discharge or be activated by the SO if the required rhythm is not picked up by the machine.

After using the simulator, the SO goes through the steps of attaching the electrodes to the patient and following the instructions shown on the screen. As many repetitions are made that are necessary for the SO to acquire confidence and competence in using the equipment. An operator's manual is always given to the SO as a reference. Sometimes if a patient is a likely candidate for the AED, a copy of

the instructor's manual is given to the SO after a discussion about the device. This gives the person an opportunity to peruse the booklet and generate questions prior to a teaching session.

One pertinent step to enhance the retention of skills and materials is to get the SO to teach someone else how to use the AED. The average session lasts for forty-five minutes to an hour. One family of eight was taught during an afternoon session, the longest time to date.

Question 9: What other skills are required by the SO?

The investigator seeks to find out if knowledge of and skill in operating the AED are sufficient for the SO to deal with a crisis situation. Indeed, what other skills/techniques would foster confidence and increase the probability of better outcomes for the patient? The American Heart Association (AHA) and the Quebec Heart Association (QHA) both endorse the use of the AED as one of the advanced measures in the event of a cardiac arrest. However, all lay persons are encouraged to be skilled in CPR and the investigator expects this to be part of the needs to be met.

CPR is done when a person stops breathing and has no pulse. The technique is to breathe into the victim and give chest compressions. The former provides oxygen and the latter circulates the oxygen to all body tissues. It can be initiated by any trained rescuer on the scene while the SO is preparing to use the AED. Also if the AED fails to recognize VF or VT and therefore, does not discharge, the SO can

continue to perform CPR until the ambulance arrives. This increases the victim's chance of a successful outcome.

Training in CPR then, is a must. The logical sequence of what to do, when to do it and how to do it are all taught in this course. All SOs are encouraged and advised to take a Heart Saver course in CPR prior to the discharge of the patient or as soon as possible. If they already know CPR a refresher course is recommended.

Question 10: Are there follow-up sessions on the AED?

In effect, the investigator assesses how retention of skills is addressed. As cited in the literature, CPR skills decrease rapidly after the first three months post training, if not reinforced or used. Can these findings be applicable to the use of the AED and how would they be valid?

According to the director, there are no follow-up sessions given in the use of the AED. At the initial training session, the SO is instructed to periodically review the operator's manual. If there are any questions, he/she is encouraged to call the director or bring the device to the next visit so clarifications could be made. The director maintains that the instructions are very simple and easy to follow as well as to remember.

Question 11: How is the device maintained?

The use of medical equipment in the home necessitates that someone there not only knows how to use it but can tell if it is actually operable. This requires periodic equipment checks. How this function is executed and by whom are the reasons for this question.

Participants are instructed during the training session to have the AED charged at all times. They are encouraged to establish a pattern for practice sessions, every month or every two months, etc. In this way, they are handling the equipment and can detect if it fails to give the necessary instructions on the screen. The machines are occasionally tested by the director for breakdown or other electrical problems. There is no set time for this check.

Question 12: How long is a patient expected to keep the AED?

Different people react differently to change. For most people, having to face a life-threatening diagnosis is very stressful. Adopting strategies to help manage the problem pose additional stresses especially if there is no definite period of time when a resolution can be predicted. For example, having the AED in the home for a specific length of time may help allay the fears of some participants and allow them to focus on things beyond the designated time frame. On the other hand, having the security of the AED indefinitely may allow other individuals to become more relaxed since they equate the uneventful passages of time to mean an improvement in their

prognosis. A dilemma arises when the participants ask for a definite answer and none can be given because of the complexity of the problem. The investigator's concern is whether it makes a difference to the participants if they knew how long this therapy is warranted.

In this programme, the AED is needed from six months to a year. These patients are followed very closely and undergo changes in drug regimen and have frequent laboratory testing to evaluate their progress. A definite time frame is never given to the patients so that they do not get more anxious if things are going slower than anticipated. It is better to let them have the worse scenarios first and then things turn out better rather than vice versa. They are better able to cope when expectations seem brighter than anticipated.

Question 13: What resource persons are available to patient and family besides you?

Materials addressing the medical and educational needs of the patients and SOs about the programme are clearly embedded in the programme and can be met easily by the director at this time. However, other needs may surface or be identified requiring a more multifaceted and multidimensional approach. Younger participants may have problems revolving around family rearing and support services. The mature and elderly clients may focus on financial stability or fear of being alone with the problem. In either case, the participants may need someone other than the

director to whom to direct specific concerns/fears. Participants may simply want to ventilate. The question then is, are present support systems adequate or are additional ones required to enhance the process?

As per the director, these are all private patients who are seen in his office. There is no other physician directly involved with the programme. Patients are referred by other physicians. If the participants have questions or problems, they are advised to contact the office or page the director on his beeper. If he is not immediately available, the call is returned at the earliest opportunity. Families are always instructed if in doubt about the patient's condition to go to the emergency right away.

Question 14: How are emotional/psychological problems handled?

Illness involves loss, whether in self-concept or lifestyle due to change. The physiological changes brought on by illness are often easier to identify than those caused by the resulting emotional stress of the said illness. The behaviours exhibited by the individual are termed adaptive or maladaptive depending on the response.

In their classic research study on the prevalence of anxiety and depression as part of the response to illness, Cassem and Hackett (1971) looked at patients whose outlook or behaviours endangered their physical and emotional well-being . Of 441 patients admitted to the coronary care unit because of myocardial infarctions, 145 (32.7%) were referred to psychiatric consultants due to anxiety, depression or

behavioural problems. Referrals were made from the first to the fourth day of admission. Behavioural problems were the third most common reason for consultation. Anxiety was the most frequent and occurred mainly on the first and second days. Depression, the second most common problem peaked on the third and fourth days. Behavioural problems exhibited were denial of illness with threats to leave the hospital or treatment restrictions. According to the authors, the study documented the premise that anxiety accompanies the transitional phase of illness and depression surfaces as the individual is made aware of the gravity of the illness.

While the patients in this study all suffered heart attacks and the study was conducted during the acute phase of the illness in the intensive care unit, one cannot dismiss the fact that the grieving stage of any illness has certain commonalties. Commonalties that are also applicable to patients having AEDs due to rhythm disturbances. Persistence of such problems as anger, depression and anxiety beyond the acute phase is the concern of the investigation. It is imperative that recognition of these problems is made by the health care professionals, so that appropriate measures can be taken to minimize the problem or even avert a disaster. As Cassem and Hackett noted in their study, interventions that helped the patients with their situation were not carried out by psychiatrists alone.

As the director of the programme stated, each situation is different. Adjustment takes time and he encourages patients and families to talk to one another.

In this way each knows what is going on. He also encourages them to talk to him about what is bothering them and intervenes accordingly.

Question 15: Who has ultimate responsibility for the programme?

Innovations involve change and the commitment of individuals and or institutions involved to take risks. The AED home placement programme like most pilot or experimental programmes requires an identifiable leader. A leader who not only shoulders the responsibility but is accountable for its operation. This question seeks to verify if such commitment and responsibility are available to the patients/SO involved with the programme at the MGH.

At the MGH the director assumed sole responsibility. All the patients in the programme are followed by the director and when necessary hospitalized at the MGH unless special tests are to be done elsewhere. All the patients records are with the director. When the patients are admitted to the CCU, they follow the normal routine of the unit, but the director monitors their progress and any changes made to their regimen.

Question 16: Do you foresee an increase in the number of patients with AEDs?

An increase in the demand for AEDs can have far-reaching effects on the programme's existence. First and foremost, it could insure its viability if the concept of supply and demand holds true. Secondly, procurement of additional devices would mean an increase in cost. Costs related to equipment, training and education and time

management of resource persons. In the latter case time to provide the essential and appropriate services demanded by the programme's initial purposes. This question seeks to determine if mechanisms are in place to handle such costs. The investigator sees these two effects, i.e., costs and supply as essential factors in the programme's viability and development.

The director maintained the AED is a wonderful machine that can save lives and definitely foresees its use increasing over the next few years.

Question 17: Besides the home, where else could AEDs be used?

The AED is a technological device which requires no advanced medical training to operate. It was designed to be used in emergency situations to help save lives. Its simplicity of use, according to its manufacturers and users to date, puts it in the vanguard of modern medicine. Research studies have show or proven the machine to be reliable and successful in a wider variety of non-medical/hospital settings. More importantly, operators of the device would not only be para-medicals and EMTs but firemen, policemen, and lay persons in and outside the home. Some predictions were made as to the device being as accessible in public facilities as fire extinguishers! AEDs in the home would be as common place as home dialysis machines where warranted. The investigator seeks to confirm whether this is seen as a probable trend for the device.

The director affirmed there will be an increase in the use of AEDs. He particularly mentioned their accessibility in sports facilities and for such operators as firemen and police. His general comments on the topic were "we are on the right track in having AEDs and teaching non-medical persons how to use them".

Persons Interviewed: Cardiology fellows

Duration: 15 minutes

Interviews with three cardiology fellows in the McGill University Science Programme. Cardiology fellows play a significant role in the development of programmes geared towards the cardiac patient as well those promoting preventative medicine.

The focus of the interviews was to learn what general knowledge the cardiology fellows have of AEDs. Specifically, were they familiar with the home placement programme of AEDs offered at the MGH? In addition, questions were asked to validate concerns/issues revolving around the training and education of participants of such a programme. (See Appendix B).

Question 1: What is your knowledge of AEDs?

Awareness of a particular kind of equipment or technology does not mean a thorough knowledge of its application, its advantages and disadvantages. Many large teaching medical centres are places where advanced technology is introduced following strict research protocols. It is here residents/fellows get first-hand

experience with or are exposed to new forms of technology. The investigator wishes to confirm this knowledge base and whether they have had any practical experience with the AED or similar devices.

The three residents/fellows have thorough understanding of how defibrillators work. They have all had occasion to use the standard defibrillator in the clinical setting, but readily acknowledged they have little or no experience with the AED. However, they could all cite patient populations where its application could be beneficial, such as cardiac arrest, repeated episodes of VT, cardiomyopathies and post MI arrest etc. The fellows stated they had familiarity with the (AIDC) automatic internal defibrillator cardioverter because they had seen or treated patients with the device during their present residency. They admitted having better knowledge of drug regimen than of the AED.

Question 2: Are you aware of the programme at the MGH?

The novelty of this programme and its unique status in a Canadian institution led the investigator to expect a much talked about programme among the cardiology fellows. As future cardiologists, they are seen as beacons of scientific advancement and innovation. Involvement with and knowledge of such programmes are considered part of their repertoire.

All three cardiology fellows denied having any knowledge/awareness of such a programme at the MGH.

Question 3: Would you consider the AED as an adjunct form of therapy in your practice?

Research findings and successful clinical trials often expedite the use of new therapies and equipment. The longer and more extensive the studies, the greater the reliability placed on the findings. As the cardiology fellows track the progress of the varied ways AEDs are being utilised they may be inclined to embrace this form of therapy in their future practice where appropriate. The openness/reservations towards AEDs must be explored to ferret out the barriers to and any unrealistic fears of this therapy and above all how the decisions are made for patient selection.

Two of the cardiology fellows saw the AED as an important technological device that has the possibility of saving lives. One, particularly mentioned its usefulness in places like sports arenas where SCD has been known to occur. Both concurred that the AED is not a primary form of therapy. "It is not a cure but a bridge" said one. Both emphasized the need for appropriate patient selection and when an event occurs and appropriate intervention by the respondent. This need, according to them, raises the issues of social implication and that of training and education. One fellow stated that the medical residents needed to be educated. They need to know who could benefit most from this therapy and the SOs who are capable for their roles. He went on to outline what he considered to be criteria for patient selection - availability, interest, and capability of the SO. The SO must have

knowledge of BCLS. For him the big issues were training/education in the use of the AED. He furthermore emphasised his willingness to learn the guidelines for the programme. He planned to discuss the topic with the director of the programme and other cardiology fellows to get better insight into its function.

Both fellows raised the question of cost in relation of life and death. They expressed the need to examine cost in terms of quality of life and life expectancy for the survivors and the ethical issues that medicine and society at large must confront in studying this problem. Both believed that with appropriate patient selection, the AED can be cost effective in the long term. They concluded that rapid intervention with the AED can reduce the varied complications associated with cardiac arrest, such as lengthy rehabilitation which drain resources. These two fellows consider this programme as part of the changing role of medicine. This shared responsibility can maximise the effects of therapy when both parties support others efforts.

The third resident interviewed took an almost opposite stand in regard to the use of AEDs by lay persons. He argued that the social consequences are too grave. Family members would have too much guilt should outcomes with the AED be negative. He asked "What is the price? Where is the social conscience?" According to him, technology has no conscience. "Yes, we have the technology, but where has the humanity gone?" He stressed that the quality of life and how much time could be bought by the use of the AED must be examined. He stated before he could be sold

on the use of home placement of AEDs, he would have to see the results of a large scale study. He did not address the issues of cost and criteria for patient selection, nor the role to be played by medicine in training/education of AED users. He would endorse the use of such equipment by paramedics. He concluded that lay persons lack the knowledge to make good, accurate assessments.

Question 4: What concerns do you have or see arising from this modality treatment?

As future cardiologists, these fellows will be faced with an increased number of treatment options to offer their patients. The use of AEDs may become more prevalent within a couple of years. This would, therefore, require that any cardiologist who participates in such programmes must weigh the advantages and disadvantages to both the patient and the practice. For example, the amount of time it may take to adequately prepare and constantly meet the needs of patients and families in such programmes could be enormous. Would they see this as an option to be offered to younger versus the older patient and why? Better yet, do you feel sufficiently prepared to institute such a programme or does it require specialized courses/training?

Three major concerns were identified by this group as having extraordinary impact on this programme. The main concern was cost and the benefits to be derived from the use of AEDs. The fellows agreed that AEDs can benefit a certain group of

patients. They were however, hesitant to endorse their widespread or public application in light of the requirements the programme demands. This raises the second concern, that of training and education of those involved. Adequate training and follow-up programmes for users of the device as well as maintenance of the equipment are vital to the success of the programme. Specifically mentioned was the training and preparation of the providers of the service to enable appropriate selection of patients. Last but by no means least was the concern for the ethical/moral and social issues surrounding the use of such advanced technology to save lives. The question raised by one fellow "where is the social conscience?" In essence, who takes responsibility for monitoring the moral if not legal implications of such programmes? Indeed, do they need such mechanisms?

Person Interviewed: Cardiologist

Duration: 19 minutes

Interviews with two staff Cardiologists

Question 1: Are you familiar with AEDs and their present use by non-medical personnel?

The interviews with the cardiologists and cardiology fellows were based on the same fundamental questions. The investigator expected the cardiologists to draw on their personal experiences and knowledge of the social and support systems to endorse or refute use of this technology. As medical practitioners, it cannot be assumed that

maturity and years of experience would dim their enthusiasm to embark on new technology or innovative practices. The same holds true for the cardiology fellows. (See Appendix C).

Eliciting the prevailing views held by medicine regarding medical acts being performed by non-medical persons is important. Does medicine actually see these practices as usurping medical authority and responsibility or rather building and strengthening a collaborative relationship between caregivers and the recipients? The outcomes of this and similar home-care endeavours could be enhanced and thwarted based popular medical beliefs. While the avenues for such ventures might be opened and welcomed by varying non-medical sectors, resistance/disapproval by medicine could hinder progress or prevent/delay institution of such programmes.

Both cardiologists are well aware of the AED. They both endorse the concept of the AED's use by specific groups, but expressed concern for the widespread use by non-medical persons e.g. SOs. One cardiologist identified the need for extensive training and education surrounding the device. The other was more concerned with the cost and the psychological effects of the SO if the patient did not survive despite the appropriate intervention. Questions this cardiologist raised were, "Did I have enough training?", "Did I do something wrong?". His most interesting question was, "How many can save?". They both expressed concern for criteria of patient selection and the benefits to be derived from this form of therapy.

Question 2: Are you willing to use this form of technology in your practice or refer a patient to the programme at the MGH?

This question covers questions two and three posed to the cardiology fellows. The difference here is that staff cardiologists can directly consult with any other practitioner in and outside the institution as they see fit. Availability of expertise and programmes that could be beneficial to their patients prompt consultations. The investigator expects to see this kind of interchange especially within a large university centre.

Both cardiologists conceded this area of cardiology is not their speciality. One stated he would refer his patients to the electrophysiologist who is better able to evaluate the patients' condition for the AED programme. He, nonetheless, stated he feared the use of this particular technology by persons who have inadequate training. His colleague stated, "I am willing to use this type of technology in my practice for a selected group of patients who meet for a specified criteria (...) I have no problems with the use of advanced technology when appropriate screening is made."

Question 3: What training/education do you expect the user of the AED to have?

This question examines the depth and breadth of what the user's (especially the SO's), training and education of the AED entails. Is it enough that the user/SO is able to operate the device competently? The user can be given the skills to operate and trouble shoot the device and avert a life/death event. However, in the case of the

SO, training must go beyond technical skills to include critical thinking and problem-solving around both the AED and the disease process itself.

In many, if not all instances there is a significant change in lifestyle for these participating in such a programme. Exploring the needs of the SO and patient and providing relevant information, resources and support services to these families become part and parcel of the educational process. The knowledge that the necessary mechanisms are in place to support them may add to the SO's assumption of the role with greater confidence. They can assumedly utter these famous words "I'm not alone in this !".

Coupled with skills in using the device and having other support services, the SO should also have skills/certification in basic cardiac life support. This course promotes assessment skills and equips the SO to intervene if the device fails or is not available should a cardiac arrest occur.

According to the one cardiologist, education and training should include all aspects of life. There must be holistic and humanistic approaches taken which consider skills, knowledge and feelings of the patient and SO. Teaching participants how to use the machine is not enough. They must be able to deal with and offset feelings such as guilt should the intervention by the SO fails. Learning to deal with guilt is a vital part of the preparation and education.

The other cardiologist was very sceptical about training non-medical personnel in the use of the AED. He states "When I think of training the first question that comes to mind is - who is attracted to the police force and ambulance services?. Are they people who like power and for what purpose? I see the use of AEDs along the lines of granting power to certain individuals and are they adequately trained/educated to use them appropriately ?"

Question 4: What future trends do you predict for the use of AED's?

Modern medicine has played a significant role in the application and propagation of technology. Hailed as a life-saver in emergency situations, the AED stands an the vanguard of this technological shift. Since 1992, the AHA has endorsed the use of AEDs in its guidelines for emergency cardiac care. Needless to say every one has not and will not embrace this recommendation especially when the use of the device goes outside the medical domain. The AHA sees the device as an important link in the chain of survival. Predictions are that more para-medical and untrained medical persons will be operating the device in future. Among the expected users will be firemen, policemen, EMTs ambulance attendants, and even lay-persons. it is therefore, imperative to have a medical perspective as to how this trend is foreseen and what barriers may be identified that might impede wide spread use of the device.

One cardiologist emphatically answered that the use of the device will increase because the public will demand it. The other cardiologist was more cautious. He

was not optimistic about widespread use of the AED due to the present financial state of our health care system. This technology will not be considered a priority by the government especially when the overall cost of the device is examined. If purchase, maintenance and service are all factored in this would be quite an expensive venture! There were no additional comments made pertaining to the use of AEDs by either cardiologist.

Person Interviewed: Patients/ SOs

Duration: 10 minutes

Appendix D outlines the basic questions posed to the patients and significant others.

Question 1: What do you know about your heart problem?

The many forms of media available in today's society allow the average person to acquire information and knowledge previously restricted to certain professionals. Medicine has lost much of its mystique through the various televised shows. Shows not only demonstrate technical procedures but give explanations regarding disease processes and treatment options. Advertisements and literature are often geared towards heightening public awareness so that a more curious, informed and responsible public is developed. Heart disease as the leading cause of death in North America has generated tremendous media coverage over the past decade. There are anti-smoking campaigns, weight and diet control programmes etc., all methods of

promoting healthy lifestyle and prudent heart-living.

This question then attempts to see whether this particular group of patients indeed knows and understands the causative factor of their illness. Just as important, the investigator learns how much Information is necessary to meet their needs (and not overwhelm them with useless technical jargon) when developing educational materials.

All patients were able to identify the cardiac problem which led to their acquiring the AED. Seven of the respondents stated they had "rhythm disturbances" - i.e. their hearts beat "too quickly and irregularly". One patient was able to link his problem to an "electrolyte imbalance." This had resulted after a strenuous game. His body chemistry went amok and he suffered an arrest as a consequence as explained by the programme director. Whether their past arrest was due to rhythm disturbance or an imbalance in electrolytes, they were made aware that it could probably reoccur. The AED was among the treatment adjuncts that was offered to them.

One patient specifically stated he would have liked more technical or detailed explanations as to how the medications affected his condition to actually reduce the chances of the problem reoccurring. He wanted to know the probability of someone having to use the AED despite the fact that a drug regimen was strictly being followed. Also he was being closely monitored by his cardiologist.

Another patient knew she has a "chronic atrial fibrillation" which had led to "ventricular fibrillation" while she was awaiting insertion of a permanent artificial pacemaker. One male patient stated he has suffered a massive heart attack and was at high risk for cardiac arrest from "ventricular tachycardia". Yet another female patient described her problem as ventricular "tachycardia". From all their responses the cardiac problem cited by the patients were of two categories, i.e., ventricular fibrillation or ventricular tachycardia both of which can result in SCD.

Question 2: How did you first learn about the AED?

The physician is often the first person to explain treatment options to patients about their illness. However, as the media make information about procedures, tests and medical break through more readily accessible to the public, it is possible that awareness of this new technology came from this source. Substantiating the information as to minute details and appropriate uses might then be left to the physician if the subject is initiated by the patient. This question lets the investigator see how informed the participants were on the topic prior to their involvement.

Introduction to the AED was made to all patients by the programme director. The patients all stated the management of their problem was discussed with them including the battery and frequency of tests, drug regimen, follow-up visits and the AED as an additional source of protection in an emergency outside the hospital. One patient stated he was made aware he was not a candidate for repeat open-heart

surgery or the implantable defibrillator. Instead, the AED was an adjunct to medical management that could allow him a form of security and freedom outside medical environs.

Question 3: What changes did you have to make in your daily living?

This question looks at the manner in which patients adjust to the sudden and unexpected changes brought on by their illness. Has the patient perceived the illness as having wrought any changes and to what extent ? Depending on the phase of the illness and the patient's coping mechanisms and personality among other things, these changes may be subtle or drastic and have significant impact on the family structure. Consideration must be given to the age, occupation and general state of health and activity level of the patient prior to the illness. If activity levels were minimal previously, no drastic changes may be expected. However, with the younger, employed socially and recreationally involved person a restrictive lifestyle could now be demoralizing. Identifying the areas of concern or issues surrounding patterns of behaviour can assist the investigator to spot emerging trends. Data collected would then be used to make recommendations as to accessing appropriate resources if and when needed, so that this transitional/adaptational phase is less traumatic.

This question elicited a variety of responses. One patient stated she had no major changes in lifestyle or daily routine due to the AED. She simply took it everywhere. Changes were due to other factors e.g. they gave up bowling because of

the inconvenience of travelling since they do not own a car. Three patients saw no changes in the lifestyle whatsoever. They continued functioning as if the machine were not around.

Four patients experienced major lifestyle adjustments. Two voiced their frustrations with the restrictions made to driving which lasted up to a year. This warranted having to rely on someone else or take public transportation. This was a tremendous loss of freedom for these two individuals. On the other hand, one patient stated having the AED allowed him greater freedom since he was previously restricted to his home. Another in this group referred to the psychological adjustment and likened the experience to a "two-edged sword". He felt a strong dependence on the machine as if "he were wedded to it". Another patient stated she would rather not have the machine but does not want her family to feel "guilty" if they could not help her in an emergency. She summed it up as "it's for my family". A male counterpart described his experience as "giving peace of mind" to his family by having the machine there.

Question 4: Were you given instructions in the use of the AED?

While patients in reality could never use the AED on themselves, having first-hand knowledge of its operation could serve two essential purposes. Firstly, if inadvertently faced with a similar situation as theirs, they could intervene and possibly save someone else's life. Secondly, the patient could also act as resource person for

the SO during dry run sessions to assess retention skills.

Understandably, there are and will be those patients who prefer to be given the least amount of information about their illness. This aspect of the situation as well as the capability of the patient to perform the psychomotor task must be considered by the trainer/educator. The option of being taught should always be given to the patient.

All patients stated they were present while their SOs were being trained to use the AED. The most elderly patient had no interest in its operation but left this task strictly to his wife. All the others learned how to use the device and subsequently taught others its operation. One patient taught two family members and found a vast difference in their attitude towards the device. She described the first SO as being nervous and overly stressed. The second was confident and felt more attuned to the machine. She, I might add, also felt better protected with the second SO as to probable outcomes in an emergency.

One husband gave instructions to his wife, following her discharge from the hospital. During the initial instruction with the director all members of his family were present except his wife. She was hospitalised at this time. All patients recounted their ease in grasping how the AED works. However, they also voiced the hope it would never have to be used on them.

Having first hand knowledge in the device's operation had several advantages for the patients. They were later able to assist SOs during practice or dry-run sessions if the sequence or steps in operation were forgotten or faulty. They had seen the ease/difficulty of learning how to operate the AED and were assured that anyone could learn to use it (discounting those with some form of physical or mental limitation). One factor was to have confidence and trust in the operator who would be facing a life threatening situation. Another significant explanation given for having this knowledge was in case they were travelling on the highway or were present at the scene of an arrest, they could use their machines to save someone else's life.

Question 5: What general feelings do you have regarding the AED?

The answers from this question provide a wealth of information to both potential users of AEDs and anyone involved in the care or the development of similar programmes for the home user. Answers fell into both physical and psychological/emotional spheres. Some answers demonstrate the difficulty participants had in giving what seemingly appears to be sound advice but in practice is contradictory to their well being.

The needs expressed by the patients can be grouped into two broad themes - physical and psychological. According to one patient the physical aspects were easier to satisfy or handle since routine practice could equip one with the necessary manual skills. All patients agreed that the instructions given in the operation of the device

were easy to understand and execute. They all stated that initially a routine was established in the home to review instructions and have practice sessions. They felt this was essential for the SO to retain skills and to ensure proper function of the equipment. One patient likened his experience to conducting "fire drills" every three to six months. Another patient's advice was - "get as many people as possible to learn how to use the AED, friends and family." Yet another strongly urged that the patient be instructed in the use of the device. Four of the eight patients admitted that as time elapsed - longer than a year - the routine for practice decreased. Two patients stated their therapy changed and the AED was no longer required. Of the other two, one is still adjusting to the device, the other patient has a non-functioning unit. To probable users, patients' advice is "make sure the battery is charged and the machine is in good working order".

From a psychological perspective patients' adjustment ran the gamut from fear to anger to total compliance/trust without reservation. All patients cautioned against becoming overly dependent on the AED to the extent that "paranoia" sets in. One patient's advice was "do as you are told", "follow instructions" was another's advice. One patient recommended a "forum" be set up to explore the psychological concerns which he found most difficult to deal with. He wanted answers to such questions as - "is this a lifelong affair?". "How long do I have to depend on the AED?". He felt he needed to address these fears that were suppressed. Another expressed his anger

in these words "I followed the rules, I led a healthy lifestyle. I did not smoke or drink, I was an avid athlete. Why me?!". One male patient was comforted by having the device since no other option was open to him. Yet, he readily admitted that he did not want to be a "vegetable", he would rather "die" than live in that state.

The advice given here demonstrates how difficult it sometimes is for the patient to differentiate between sound and contradictory advice. "Forget about the machine and continue life as normal". On a more feasible level another suggested to "make sure whoever is to use the machine is comfortable with it and not afraid.". There was consensus from patients that a good family/patient and doctor relationship should exist.

Significant Other:

Question 1: How/when did you first learn of the AED?

This question was also posed to the patient. Expectations are the SOs awareness of the device matched that of the patient. Did members of either group have prior knowledge of AEDs and to what extent? The investigator's concern here was if awareness existed how much of this was fact or myth and what clarifications needed to be made, if any.

Six respondents in this group were first informed of the AED by the programme director. The other two learned of the machine from the patient.

Question 2: What instructions did you receive in the use of the AED?

The basic requirements needed to operate the AED is the same for the medically able to manipulate the device as well as follow the sequential steps entitled by the manufacturer. The investigator seeks a general idea of the complexity or simplicity involved in this particular teaching/learning process. Learning what strategies worked best or what areas seemed more problematic would allow the investigator to explore these more fully so that any model/design for instruction developed would enhance the learning process.

The programme director took ultimate responsibility for training the SO in the use of the AED and disseminating the necessary information about its maintenance. While the participants all received the same basic instructions there was variation as to where sessions were given and how long they lasted. Variation depended on the size of the group being instructed and the number of questions that were generated. According to the learners they were provided with written information - user's manual - about the AED. This manufacturer's booklet has step-by-step instructions with pictures on how to use and maintain the machine.

More importantly, verbal instructions were given by the director during the actual practice sessions. He stressed the need for good maintenance of the machine by having it charged at all times. The components of the machine were explained including attachment/detachment of the battery from the machine and proper cable

needed for charging that ensures safety. To determine whether the SO understood the instructions, return demonstrations had to be made until the director felt the SO had mastered the skill. The SO was then expected to teach someone else as a means of insuring clarity and enhancing his/her retention skills.

Three of the SOs stated they received instructions at the bedside. They felt comfortable in the setting, and space was adequate since there were only three persons present. They stated they did not feel harried and left confident they could perform their task. They were instructed to hold regular practice sessions at least once a month initially and then every two to three months when they felt undoubtedly comfortable with the device.

In two instances, the patients taught the SO at home. In one case, the entire family of eight was taught by the director in his office. This provided for adequate space and as much time as needed for all the members to competently use the equipment and also have questions answered in order to alleviate their fears. This session lasted about four hours unlike the usual hour it takes to instruct the SO. The patient later taught his wife how to operate the machine after her recuperation from surgery. Incidentally the machine used by this family differs from the standard one used by all other participants in the study. This machine has a voice-activated feature for instructions instead of the visual display on the screen.

To help launch the inception of the programme in a Canadian hospital, the first teaching session was demonstrated on CTV. The SO was actually instructed during filming with all the salient details for use and maintenance of the machine.

The most recent SO in the group was instructed at the bedside by the investigator. A demonstration was earlier given by the director to the patient in the investigator's presence. In addition to providing the user's manual, the investigator used coloured diagrams in the session to facilitate understanding of the underlying cardiac problem to both patient and SO. During the session, the features of the device were explained. A demonstration was made using the patient to show how to adequately prepare the skin and the exact placement of the electrodes. Steps were outlined in the process of when to call for help especially if the SO is the only person at home. The process was reviewed a few times clarify/answering questions as we went on. The session lasted about three quarters of an hour. This time-frame might reflect the fact that the patient had earlier gone through the procedure and could anticipate the role he was to play. All general information with regards to upkeep of the machine was reviewed. The SO gave a return demonstration. She expressed the need to go over the manual at home where she could further process the information and see if there were more questions. All participants voiced satisfaction with their introduction to the use of the AED.

Question 3: Did you ever use the AED since the training session?

Personal experiences have profound effects on getting others to join groups or participate in events. Testimony of successful experiences often gives others the confidence they need to achieve the same results. The investigator hopes for a success story that would allow the SO to know that they can actually save lives.

None of the SOs has ever had the occasion to use the AED.

Question 4: Have you ever dealt with an emergency? What is your usual reaction?

Reactions to unexpected or crisis situations trigger in everyone what physiologists term the “fight or flight” response. The degree to which this response is overtly manifested depends on the individual and the situation. Some individuals are able to perform a task well despite feelings of fear and nervousness. Others are so shaken they become immobilised. While past experiences could indicate particular response patterns, there are however, no guarantees that the same behaviours would always be exhibited. This question lets participants reflect on how they cope with emergencies and stress. It is hoped they can formulate a mental contingency plan to deal with the event for which they are being prepared. The physical component maybe mastered after several practice sessions, yet the emotional side may go unexplored and in fact may be the barrier to a successful outcome. In a teaching module, tips on how to control or decrease anxiety levels can be inclined without

oversimplifying what could be a complex problem.

Half of the SOs were wives who had raised families and stated they felt comfortable handling emergencies. All SOs did voice some "fear" that they might not be able to respond appropriately should the occasion arise, since no other emergency would have the same impact. One SO had to call 911 since having the AED in the home. Her husband suffered another heart attack while she was out. On returning she recognised the signs and called Urgence Santé. Her husband was conscious and therefore did not require application of the machine. The other three SOs also stated they felt they could handle the situation, should an event occur.

Question 5: What other skills did you have to help you cope?

This question probes the ways participants prepare themselves to handle this crisis which is unlike any other. Reliance on the skills acquired to operate the AED can suffice. But additional preparation, like being able to perform cardio-pulmonary resuscitation is also essential. How and where to get information on CPR courses may not be readily available. The investigator can include a list of such institutions or centres in the instructional package.

All SOs except one has had courses in CPR and readily stated this was a must for family members. The one respondent who did not take the course, stated he follows all the medical shows on television and knows what to do.

Question 6: What lifestyle changes did you have during this time?

The balance that propels the activities of daily living is always shifting. Man often makes these adjustments quite easily. There are some events so disruptive that the taken for granted mode of coping is thrown off kilter both physically and emotionally. Some individuals may find themselves unable to identify what these changes are or the extent their lives are different. This state of "shock" or disequilibrium may last for a short period or be prolonged. This question hopes to ferret out the recognition and the extent of change the SO experienced during this period. Responding to this question may provide the SO with the opportunity of putting aspects of the change process in place. The investigator can use the data as a frame of reference to show similarities and differences in the change process in an instructional model.

Answers to this question reflect both the physical and psychological adjustments the SO experienced during this period. It is, however, interesting to note that four of the SOs stated they did not make any changes in lifestyle. Some of the descriptors they use to relate their story say otherwise.

From all respondents an emotional component was evident. One husband said he became more "alert" in his daily routine. He related his family's reaction to the curiosity shown to the "box" by neighbours and friends as being a family joke. The family was able to laugh among themselves at the "addition" to the household. The

gravity of the situation was offset by their periodic release of tension through laughter. His apprehension was relieved through the team spirit his family and neighbours developed to cope with the situation.

One wife allowed her husband to make the decision when they would take the device with them. It was taken only on long trips usually across the border. One can assume the psychological benefits of having the machine on these occasions. This SO stated she made no changes in lifestyle.

Another wife described her husband's reaction to the AED as "leery". She felt safe having the device around. This measure of safety was cut for the past three years when the machine became inoperable. After a fire in the home, she discovered the machine no longer works. Also the company in Quebec from which it was purchased has gone bankrupt. Any repairs will have to be carried out at the headquarters in the United States. Her biggest concern was the cost it might incur and whether it was worth it since they have never had the occasion to use the AED in the past eight years. As senior citizens on a fixed income, she felt they might not be able to meet any excessive charges if the machine were sent away.

The second SO, who categorically stated he made no changes in lifestyle, went on to say the couple spent most of their time at home because "we enjoy each other's company".

The SO who was the first to be introduced to the AED, was less than a year married, when her husband suffered "sudden death syndrome" at age thirty. A dramatic course of events followed including the husband's placement on life support systems. After a lengthy hospitalisation he was discharged with home placement of the AED. This SO readily admitted she had never dealt with an emergency. Her greatest fear was that "I would have to use it!". She described her "anger", "frustrations" and "helplessness" at the situation she had to face over the coming years. Not only was she adjusting to the role of wife but to the probability that she might have to use the device.

The last couple to be introduced to the AED are still adapting to the process. The SO admits she is still getting over the fear. Consequently she does not sleep soundly. She, however, feels she cannot categorically state all the adjustments she had to make at this time but could make a better analysis later.

There is more of a common trend that emerges from the physical adjustment to the AED. Six of the eight couples initially took the device with them everywhere. Places where the AED became a constant companion were church, shopping, movies, dinner etc. Three SOs noted the device was taken on long trips to the US, travel within Canada and as far as Great Britain. The SO who took the device to Britain especially mentioned the weight of the AED made it difficult to carry manually. She used a shopping cart for routine transport. One other user commented on the weight

of the device.

Two of the couples never took the device outside the home routinely. The youngest couple in the group attended movies, and went out to dinner without it. In contrast, the oldest couple continued to volunteer at an Extended Care Facility four times a week. This involved transporting patients via wheelchairs to and from activities. The couple has recently decreased their volunteer schedule to once weekly. The pattern of travelling without the device has not changed.

According to replies from SOs routine maintenance and practice runs with the AED varied with the length of time the couple had the device. Initially all respondents cited routine checks to ensure battery was charged, reading of the user's manual from every two weeks to every six months. One wife said she religiously followed a two week review for one and a half years until her husband's therapy changed. The AED was subsequently given to someone else. One SO's son is an ambulance attendant, he taught the team of eight CPR and routinely put them through practice runs during the eight months the mother had the machine. On the other end of the scale one SO admitted to having placed the AED in a cupboard where it was forgotten for over a year. This couple has had the device for six years. The SO stated he needs to have the device readily visible. The AED has been taken between homes of this couple who has residences in both Quebec and Ontario. The husband had to give up part-time farming and horse rearing to adjust to his change in lifestyle.

The site of storage or generally where the AED was/is kept vary. Most couples stated the device was kept anywhere in the home. One SO emphatically stated it could be tolerated by her husband anywhere in the home except the bedroom.

Question 7: How long have you been in the programme?

Affirmation of both the physical and emotional well being of the SO may be seen through this question. The expectations are the initial period as being very stress-provoking. With the passage time the stress level decreases because no untoward event has occurred which signifies other therapies are working and the chance of having to use the AED diminishes daily. This could also result in the SO becoming less vigilant. There is the need for dialogue between physician and SO to confirm the state of the situation and indeed be sure the critical period is over and chances of SCD for the loved one falls within the same parameters as that of any general cardiac patient. Indeed, if the situation has become open-ended what adjustments need to be made (if any) by the So to accommodate this?

The least amount of time the AED was held by a family was three months. The longest time to date is eight years. The average time is three years.

Question 8: What resources/support systems were there available to you?

Compensation is the term used to describe the physiological adjustment the body makes to stress. This mechanism however, like most resources used for emergencies is limited. Prolonged exposure to constant stress with no means of

physical or emotional relief and or support can lead to system failure. In this case, the SO who is bombarded by multiple stressors for a variety of reasons, needs to have the means whereby the levels of stress can be relieved or controlled. If the frustrations are not vented the SOs can also become "patients" due to other causes. An assessment of what is place to address these needs and concerns identified by this group is borne out by this question. The investigator can consequently make appropriate recommendations for additional or extended services based on the data collected.

All eight SOs except one have taken CPR courses. One couple has no children, the closest person from whom they got support recently passed away. One patient is young and unmarried. Her SOs are boyfriend and mother. Two other couples are parents of small children less than ten years old. The remaining four couples all have grown children as many as six in one family. These children are either away at school or married with families of their own and not immediately available to the parents at all times. Most couples stated they relied heavily on each other for both moral support and strength. Medically, support was given by the director of the programme who followed them as private patients after discharge from hospital. Care was individualised to suit the needs of each family. Progress was monitored according to specific drug and test regimen.

Question 9: Would you have benefitted from a support group? How?

There are occasions in some individuals lives when the need to share with and hear from others becomes extremely important. Often what these individuals seek or need is not necessarily professional help or advice. Rather, it is the opportunity to relate to other's whose circumstances have been or are similar and learn how they too can overcome what might appear to be overwhelming odds. Here, the emotional component that blocks objective discussion with family and friends is removed and frank dialogue can take place. Needless to say that all individuals could or would benefit from a support group. Two questions arise. What other options are available to the individual participant? Would a support group be appropriate/beneficial to the participant?

Six of eight respondents did not want to be part of a support group. Reasons cited were, "my family and friends are my best support", "I do not have time to participate in such an endeavour". One respondent when further questioned, stated he could have benefitted from being able to talk to someone, not necessarily a doctor. He needed someone to whom he could air his fears and anxieties during his wife's pregnancy when he was petrified an arrest might occur. Two participants, both female, strongly believed they would have benefitted tremendously from a support group. One wanted to initiate such a programme but never did for many reasons, one being the scarcity of SO's.

Question 10: What recommendations would you make to those involved in the programme?

The benefits that can be derived from first hand experience are always invaluable. This reality-based information can be analyzed and pertinent findings incorporate into the teaching/learning model. The feedback which the investigator gets from this question is hopefully beneficial to all participants in the programme.

All recommendations made to those involved in the home placement of the AED are below and fall into three main categories - Knowledge, physical and emotional concerns and resources.

Knowledge/Training:

1. Give easy step-by-step instructions.
2. Use graphics, symbols to illustrate important points.
3. Keep family informed, not necessarily about the machine, but what is going on.
4. Inform oneself about the problem as well as the machine.

Physical Concerns:

1. A lighter machine is needed - weight of machine limits user.
2. Always keep AED charged and ready for use.
3. Keep machine where it is visible.
4. Read the manual regularly.

5. Have knowledge of CPR. Take a St. Johns' ambulance course.
6. Have follow-up sessions on AED.

Emotional Concerns:

1. Introduction to the AED should prepare SO mentally to take the responsibility:
i.e. what to expect.
2. Regard the machine as "portable insurance".
3. Have a number family/patient can call to alleviate feelings of anxiety. This person needs not be a physician merely someone to talk to.
4. Have a physician who talks and answers questions up front, clearly and honestly.
5. Talk to someone in the know to build a trusting relationship.
6. Form a network with other patients and families.
7. Be open with one's partner, make sure partner is open about fears and feelings.
8. Get psychological counselling re: problem if the need arises.
9. Do not allow AED to place restrictions on your life. Continue to participate in activities you like if you can.

The lists of concerns/issues identified by the participants, undoubtedly have educational implications for those involved with the administration and planning of the AED home placement programme. Problems which can be remedied by training

alone are highlighted. In addition, psychological concerns which will require specific forums/avenues to individual or group needs have also surfaced.

DISCUSSION

The interview with the director of the AED home placement programme indicated he believes the programme meets a definite need of this selected group of cardiac patients. He strongly advocated its continuance and believes that AEDs will have a wider application in the future. He maintained that patients and families be taught how to operate the device because they are capable of such undertakings and can make a difference through effective and efficient intervention - they can save lives.

From these responses, one can postulate that the use of AEDs in the home is beneficial. The probable benefits to be derived from such programmes can be substantial. For example, the preservation of life and the reduction of complications due to timely intervention are important benefits to both family and society. Overall, successful intervention can translate into reduced hospitalization and rehabilitation periods, quicker reintegration into the workforce for the younger and still highly productive worker and fewer long-term side effects that may require on-going medical treatments - chronic hemodialysis secondary to renal shutdown suffered during the arrest.

Analysis of the topic demonstrates its inherent complexities which must involve taking into account the perspectives of both patient and SO/family. Most patients have stated they welcome the AED as it provides security for the SO/family. The results indicate that they themselves disliked or took exception to its presence because it

reminded them of their human frailty/mortality and to some extent their dependence on others. An important concern that is evident from the study is the limitations such a condition imposes on the victims. During the early phase of treatment, patients are restricted from driving for up to a year after the event. This constrains the victim to wait on others, or to take public transportation, both of which proved to be highly frustrating to those who were before totally independent.

Regarding knowledge acquisition around the use of the AED, learning how to use the AED was not problematic for the patient. Only one patient unequivocally did not want any such teaching. The others knew that any opportunity they would ever have to use the device would mean they were the doers and not the recipients of such a service - a more comforting thought to them.

The SOs have shown great fortitude in dealing with this multifaceted problem. Their role included acquiring the skills necessary to operate the AED, learning about the causative medical condition as well as giving support and comfort to their spouse.

They have all stated they followed the director's instructions closely and felt comfortable with these. They reviewed periodically, if not systematically the steps needed to perform adequately. As time passed, the study shows some SOs lapsed in their routine for reviewing and maintaining the device.

The overall comment was the AED's presence was or is reassuring. To date, no SO has had to make this intervention so the actual success/failure has not been proven

or documented in this study. The SOs have been able to adapt well to the physical presence of the AED. Transporting the device has been problematic for some who find it too heavy to carry but adjusted to this by using carts or trolleys for transport. The most troubling concern voiced was the emotional states or coping mechanisms the SOs used to help face the situation.

Many SOs stated they relied heavily on family members and close friends for emotional support. Where there were no family members or availability was impossible, the couple became the resource person for each other. When asked if a support group would have helped, only two SOs wanted this type of service. Perhaps a different forum besides group discussion - for example, a one on one meeting with a professional or paramedical person might be the answer.

The responsibility that the SOs assumed and the empowerment entrusted to them by such a programme cannot be trivialized. More and more families/SOs are getting involved in the provision of care to family members. Care that includes home dialysis, administration of parenteral medications and enteral feedings, procedures that all require not only psychomotor skills but cognitive and affective skills. Preparation and follow-up of such families to assess coping are certainly warranted. In the case of the AED programme, it may mean allowing the SO to fully explore what the situation means to them, especially what perceptions they hold of a failed intervention. The study has shown that thoughts surrounding such an event is constantly with most of the SOs

interviewed.

Further exploration of the topic was made through interviewing cardiology fellows and cardiologists. This group basically addressed three main issues - preparation of the patient and SO, benefits of the programme to patient and health care system (society in general) and their own involvement (from preparation through delivery of services). There was consensus that adequate preparation of patient/SO is vital. Preparation must be holistic in approach to ensure that both the physical and emotional needs are met. There was some disagreement about having a generalized public programme where the AEDs can be used by others e.g. ambulance attendants, firemen and policemen etc. One cardiology fellow and one cardiologist took exception to having this device placed in the hands of non-medical personnel or persons not suitably trained. They see the use of this advanced technology best suited for the clinical areas where control is more stringent. The others in this group preferred to make referrals to consultants versed in this specialty or ensure that cardiology fellows are given more exposure and participate more in such programmes.

Based on the findings from all the key players in the programme, the investigator identified the need for a more comprehensive instructional intervention. This intervention is aimed at primarily meeting the needs of the patient/SO with emphasis on the why and how of instruction. The existing materials developed by the manufacturers of AEDs stress user skills and techniques. However, this study has shown through

comments from the SOs, that the technical skills are the easiest part of the problem to handle. The other learning domains- cognitive and affective- need greater attention/development so that problems and concerns arising from the AEDs' presence in the home are better understood and managed. Phase Two of this thesis outlines an instructional programme aimed at addressing those concerns borne out by the needs assessment. The general findings were: both patients and SOs need more emotional support. Six of the eight paired participants expressed apprehension about dealing appropriately with the crisis should it occur. Participants were afraid of forgetting the proper sequence of steps or even becoming frozen because of fear. These concerns indicate greater emphasis being placed on meeting the affective and cognitive needs, not only during the initial training period but throughout the time the AED is in the home.

Other concerns that came out were the need to educate medical personnel who might be involved with these patients. The Cardiology fellows interviewed in the study all denied any knowledge of the programme's existence. They could be an untapped resource for these families in a variety of ways, including educational support.

Another concern was that of attitude. Both the public and medicine must be partners in any home care programme. If the new trend in our society is to have more community health care initiatives, then both players - medicine and the public - must be adequately prepared and willing to execute their roles. This instructional design guide pursues the concept of implementing a comprehensive, holistic training programme that

addresses the spectrum of needs of the participants and not only the psychomotor skills as addressed by the manufacturer's manual.

CHAPTER FIVE

TRAINER'S GUIDE - PHASE 2

The AED home placement programme was instituted at the Montreal General Hospital to meet the needs of a specific group of cardiac patients who have survived an episode of SCD and are at risk for subsequent episodes. Provision of this service as an adjunct to other forms of medical and surgical therapies was based on specific patient criteria. The philosophy is that timely and appropriate intervention for such victims can be beneficial to both patients and society. For the patient, it can mean preservation of life without the myriad of complications that could have resulted from the body's prolonged lack of oxygen due to the arrest. As a consequence, the victim has a better chance for decreased hospitalization, a shorter rehabilitation period and a quicker reintegration into society. Thus, the resumption of a productive life is probable. The AHA was so convinced of the need for early intervention with advanced life saving techniques like AED application, since 1992 it has strongly recommended its use by first responders where necessary. This then advocates having AEDs in ambulances, outside the critical care setting such as general medical/surgical units, public facilities and in some instances, in the home.

AED's are technological devices used for restoring the heart's electrical system to normal when a lethal dysrhythmia like VT/VF occurs. The devices have automatic or semi-automatic features which when placed on a victim have the capability of analysing the victim's heart rhythm and either automatically delivering a shock based on this analysis or, in the case of the semi-automatic device, advising the responder to deliver the shock. The most significant feature of these devices is their ability to interpret cardiac rhythms. As a consequence, the responder does not have to have any knowledge of cardiac rhythms. The responder then correctly attaches the victim to the device, turns it on and follows the instructions displayed on the machine.

Why the AED in the home? It has been shown that sixty percent of those cardiac patient who experience SCD do so in the home or outside the hospital setting. While criteria for selection of patients for the programme rests in the medical domain, the training and education surrounding the device and heart disease can certainly be addressed by para-medical personnel like nurses.

As a part-time nurse clinician educator in cardiac/critical care setting, the investigator has the opportunity of interacting with the patients and families who have such diagnoses as SCD. The needs of any cardiac patient cannot be minimized. However, those with a diagnosis of SCD indeed face profound psychological and physical needs: the latter of which can involve the SO should the event occur in the home or away from medical facilities.

Appropriate intervention by the SO who is physically able and mentally capable of this undertaking will then depend on adequate training and education. The intervention requires the integration of cognitive, psychomotor and affective skills to increase the probability of a successful outcome.

Specifically, data obtained from the needs assessment conducted with the key players in the AED home placement programme confirm the need for appropriate preparation of all those involved. While emphasis remains on training the SO in the use of the device, other educational needs and concerns must also be given adequate consideration. The emotional needs of both patient and SO were strongly identified. For example, the inner conflicts that assail both parties were identified, concerns which are often not voiced with the hope that by ignoring these stresses they will be resolved in time. Again, if comparison could be made to those patients whose diagnosis is SCD, but who do not have the AED in the home (this study did not include this group of patients), would similar stresses or concerns be identified? It must be remembered that exclusion from the AED home placement programme rests on such factors as absence of a SO in the home, impairment of the SO's mental or physical status, no desire by the patient or SO to participate in the programme or the patient's state of health and not the diagnosis. Can it then be assumed that those with a diagnosis of SCD but without the AED or an implantable defibrillator have more emotional stresses? Do they make more visits to the physicians's office and the emergency department? In essence, how do they deal with

some of the common emotional concerns/problems surrounding their condition? All the SOs in this study have attested to the great emotional support they derived from having the AED in the home or available to them. Although in no instance was it used, they all felt a sense of security because of its presence. The question now is, can other services be made available to complement those given by medicine to help allay some of the emotional strain the participants have. For example, support groups may provide a much needed forum where family members could express their fears and share the overall experience.

This resource guide is designed to better meet these identified needs and establish a continuous guide for the user in that it can be referred to at any time (refresher course or review session). The overall purpose of the guide is to provide guidelines for patient/SO and anyone directly involved in the training and educational aspects of the programme. The guide is not meant to replace the Operators' manual or other forms of media provided by the manufacturers of AEDs. It merely supplements these, by including relevant information pertaining to concerns voiced by key players. It is a resource which affords those involved a reference on main issues about the AED home placement programme.

The proposed goal statement for this guide is : Given a specific group of cardiac patients namely those in the AED home placement programme, participants will be able to consult the manual for information regarding probable causes of SCD; instructions

in the use of an AED, and name of designated centres that offer CPR courses.

Instructional Design Model

The instructional design model on which this resource guide is patterned follows that advocated by Dick and Carey (1990). The framework constitutes a ten step process beginning with the identification of instructional goals and ending with evaluation. Formative and summative evaluations were not conducted because no new participants were enlisted to the programme during the time of this study. Phase III gives an evaluation of the programme in its entirety rather than the educational resource guide. In Phase Three, the investigator also used the principles of human learning as described by Gagne and Briggs (1974) in the development of the resource guide.

Learner Analysis

Setting

Information and practice sessions about SCD and the use of an AED can be given in a variety of places. The most commonly used sites are the patient's bedside, the doctor's office and designated classrooms. Often the person giving the information or session arranges these to suit the convenience of the learner and may opt for the patient's bedside to allow the patient's participation/presence in matters pertaining to his/her care. This also allows both patient and SO to get the information and any answers about the venture at the same time.

Assessment of the participants readiness for the teaching/learning process must be made prior to any instruction. Hospitalization of these patients can vary from ten days to three weeks. Assessment of readiness can be gauged against the participants' physical and mental states, i.e., the types of questions being asked and the plans for discharge. During the early phases of treatment, the patients are often confined to their immediate surroundings. This ensures continuous monitoring and allows for immediate and appropriate intervention to be made if an emergency arises. As the patient's condition stabilizes, he/she can ambulate in the corridor and the solarium/conference room while being monitored via a telemetry system. Telemetry is a portable monitoring system that transmits the patient's ECG rhythm to a central monitoring station where continuous viewing of the heart's rhythm can be made. As the patient's condition improves, boredom and restlessness set in and the patient often becomes self-absorbed and frightened regarding the prospects of discharge. This time can be ideal to initiate teaching.

It can serve to refocus the patient on the positive aspects of his/her condition and learn about having the AED available in the home. It can also serve as the time to prepare the SO for the patient's discharge, to learn how to operate the AED and to have any pertinent questions answered.

When sessions are given away from the clinical areas, patients may or may not be present. In all cases, measures to ensure privacy for the learners are taken. In cases

where patients share a room the operative word is not privacy but awareness by all regarding seeking help if the patient appears in distress or looks well.

General Characteristics

The target population of this module is actual as well as potential or emerging participants in the AED home placement programme, participants whose aim is to support the victim at risk for SCD. In order to render this support to the victim, the participant must have knowledge of the disease process, be able to recognize the signs and symptoms of a cardiac arrest and acquire the necessary skills to make an appropriate intervention. Almost any adult can learn these skills. However, this person must also be able to make decisions and act promptly when faced with a life threatening situation.

Learner Characteristics

Data from the needs assessment indicate learners are scattered along the age continuum ranging from the mid-twenties to the late seventies. Extreme range of age has not been a deciding factor for exclusion or inclusion from the programme. Instead, inclusion is based on the participant's willingness to take on this responsibility and the participant's ability to intervene based on decision-making powers and general coping skills. Many participants in the study stated they handled stress well and did not doubt their ability to respond appropriately in the event of an episode of SCD. Most participants voiced apprehension and even hoped that they will never have to deal with the event.

The essential needs that were evident in this study fit into all three taxonomies of learning. The cognitive domain deals primarily with intellectual abilities/skills which are required. The SO must move progressively through the hierarchical levels of learning as advocated by Bloom (1956). The SO begins by learning facts about the disease process itself, how the facts relate to different concepts and applying those concepts in the correct use of the AED. Finally the SO learns to assess the outcome of the intervention during a crisis.

The use of the AED involves a large psychomotor component to ensure mastery of the manual skills. Mastery involves co-ordinated manipulative movements carried out in an organized, sequential fashion. Needless to say, the SO must have intact gross and fine motor reflexes to perform adequately.

The affective domain as identified in the needs assessment, must be addressed because the great emotional stress may influence the intervention and outcome. The design must therefore focus on the attitude and value the SO has in regard to this situation. The SO's personality and lifestyle may dictate how he/she will respond to the crisis.

Academic Level

Participants in the programme show a diverse level of academic and career/professional attainments. This leads the investigator to assume that almost any one can acquire the knowledge, skills and attitude associated with the patient's clinical condition

and the operation of an AED. Success of the teaching/learning venture would, to a great extent, rest on dissemination of clear and precise information. Information should not be bogged down with medical and technical terminology but should be simple, well-placed and delivered in a logical sequence.

The AED used in this study required the SO to follow written instructions that were displayed on the screen of the device. Therefore, this particular feature would warrant at least a grade eight literacy level. There are also voice activated AEDs (the one exception in this study) which would be more amenable to the non-literate participant, or even those with some decreased visual acuity. To enhance learning for this non-literate group, as well as the more visually inclined learner, pictures and diagrams can be used to illustrate salient points. This gives everyone that meets the specified criteria an equal chance to participate should a reading handicap exist.

Language

The MGH maintains a bilingual status, although the AEDs used in the study were designed to operate in English. The ethnic background of the participants is varied and members were drawn from both official language groups.

Instructional Analysis

The instructional analysis chart depicts the sequencing of objects as evident in the goal statement at the top of the hierarchy. The four components that comprise the goal are shown in the next step down. Each main objective can be learned independently but

the inter-relationship or cohesiveness of the four fosters goal attainment. Each main objective states the overall learner output upon its completion.

The analysis takes into account prior discussion the patient and SO have had with the attending physician about the various treatment options available to them e.g. surgery, drugs, implantable defibrillator etc. Therefore, this knowledge will serve as the entry level skill for this module.

Objective 1: The participant/SO will be able to name the specific problem that leads to his/her SCD

This objective is further broken down into subskills and an entry level skill. Mastery of all the subskills allows the learner to meet this objective. The skill is knowledge-based and stands at the lowest level of the cognitive domain. However, without this knowledge the learner will not be able to properly support the victim in terms of potential risks factors, e.g. avoidance of cigarette smoking, diet and weight control, exercise tolerance and stress management.

Objective 2: SO/participant will be able to describe the signs and symptoms of an arrest state.

This objective requires the learner to identify what the victim would look like if an arrest occurred. It involves both critical thinking and keen observational skills to ensure recognition of this state.

Objective 3: The SO/participant will know where to acquire CPR training/basic life support skills.

A mandatory requirement for the SO/participant is the acquisition of CPR training. To decrease the level of anxiety and facilitate discharge planning, centres where these services are given will be discussed/identified.

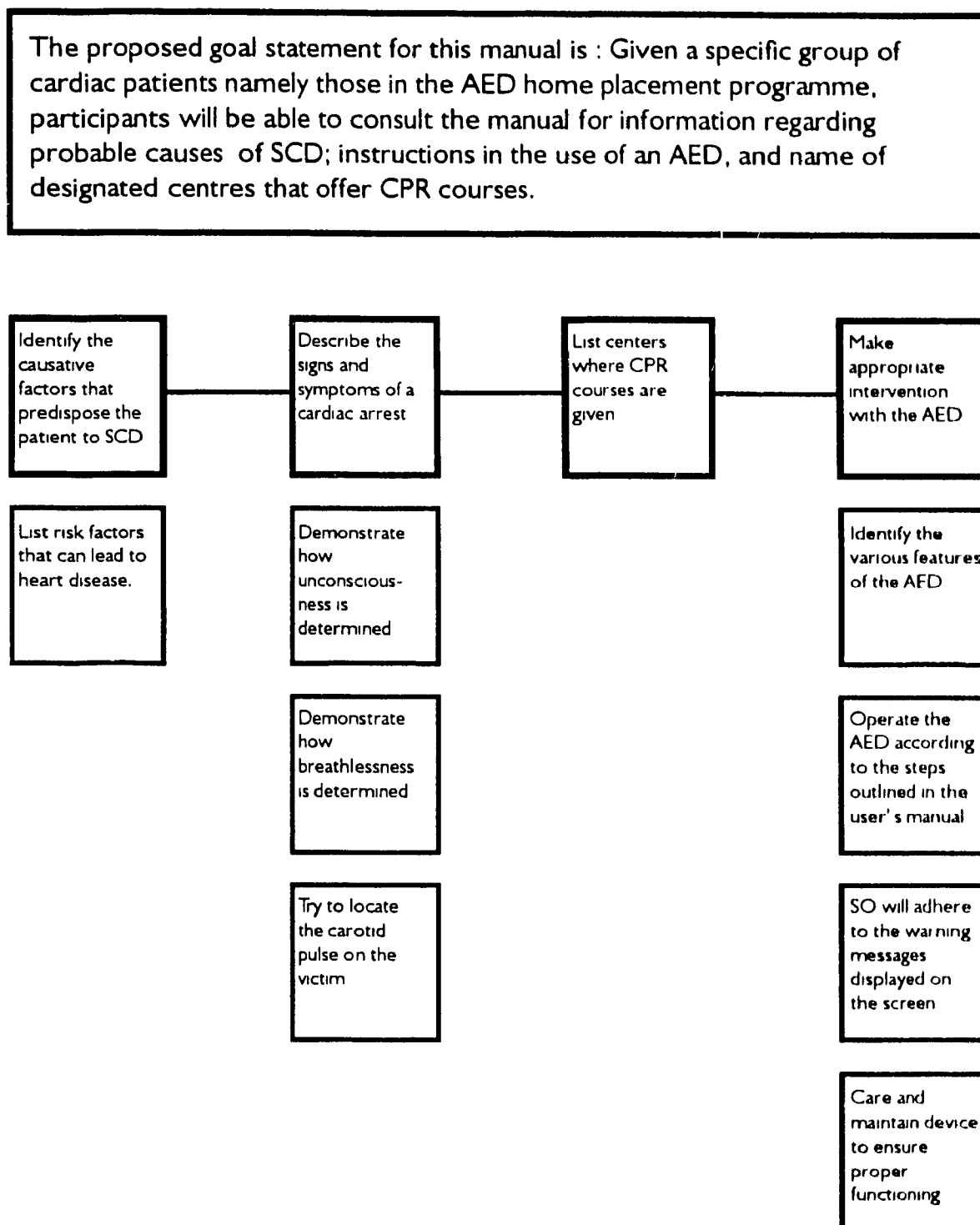
Objective 4: The SO/participant will be able to make the appropriate intervention with the AED.

This objective is paramount to the SO's successful use of an AED. It involves several subskills to ensure mastery, one of which is to demonstrate how the AED is used as outlined in the operator's manual.

The instructional analysis chart shows the progression through which the learner moves to acquire the knowledge and skills to achieve a competent level of functioning (See Figure 1).

Figure 1

Instructional Analysis Chart



Criterion Referenced Test Items

The following is a designed Evaluation Chart which contains the objectives derived from the instructional analysis process. The chart also contains the test items developed to ensure the learner has mastered the objectives outlined. The objectives are designed to fit the criteria as suggested by Mager (1984):

1. A description of the behaviours the SO/participant is expected to demonstrate.
2. The conditions under which the demonstration will be carried out
3. The criteria for accepting mastery of the demonstration/performance.

Each test item measures what the learner must know or do after completion of the objective. However, some items require a decision-making process in order to arrive at a solution. Higher level skills of synthesis and evaluation as discussed by Bloom are not part of the process.

It must also be borne in mind that one hundred percent mastery of all the technical skills is required. Nonetheless, the circumstances under which a **real** versus a **mock arrest** occurs are very different. A number of unforeseen or uncontrollable events might intervene to cloud or prevent a successful outcome. The performance of the SO may or may not then be the determining factor.

Design Evaluation Chart

Skill: Entry skill 1: Identify heart disease as the leading cause of death in North America.

Performance

Objective: Given several names of diseases the SO/participant will be able to accurately select heart disease as the leading cause of death in North America. For example, kidney failure, diabetes mellitus, cancer and AIDS all have lower death rates than heart disease.

Test item: Which of the following diseases has the highest death rate in North America AIDS, diabetes, heart disease or cancer?

Main skill 1: Identify the causative factors that predispose the patient to SCD.

Performance

Objective: Given specific identifying terms, the SO will be able to accurately identify the causative factor of the SCD the patient experienced or may experience. The list must include ventricular tachycardia and/or ventricular fibrillation.

Test item: Name the cardiac problem that caused **your** loved one to suffer SCD.

Subskill 1: List risk factors that can lead to heart disease.

Performance

Objective: The SO will list diet, age, sex, cigarette smoking, lifestyle and stress as contributing factors in the development of heart disease.

Test item: List four risk factors that can lead to heart disease.

Main skill 2: Describe the signs and symptoms of a cardiac arrest.

Performance

Objective: The SO will accurately describe unresponsiveness/unconsciousness, breathlessness and pulselessness as the cardinal signs of an arrest state.

Test item: Describe the signs and symptoms of a cardiac arrest.

Subskill 2:1 Demonstrate how unconsciousness is determined. SO will correctly demonstrate three ways by which the state of unconsciousness can be determined.

Performance

Objective: The SO will include at least two of the following means of establishing unresponsiveness (a) calling the victim by name while shaking or touching part of the body, (b) using a closed fist to rub the centre of the chest (sternum) or (c) squeezing the earlobes to induce mild to moderate pain.

Test item: SO will demonstrate two ways to determine unresponsiveness.

Subskill 2:2 Demonstrate how breathlessness is determined.

Performance

Objective: The SO will include the use of **three** senses to make this assessment. **Look** -looking at the victim's chest to see if it rises and falls.

Listen - position his/her head close enough to the victim's face to hear the sound of breathing.

Feel - in this position the SO can feel the breath on his/her face if/when the victim exhales.

Test item: Describe/demonstrate how you can tell if the victim is breathing or not.

Subskill 2:3 Locate the pulse on the victim to find out if the person has a heartbeat.

Performance

Objective: The SO will accurately locate the site of the carotid pulse.

Test item: Locate the site of the carotid pulse.

Main skill 3: List centres where CPR courses are given.

Performance

Objective: The SO will be able to list three centres where CPR courses are given to the public.

Test item: List three centres that offer CPR courses to the public.

Main skill 4: Make appropriate intervention with the AED.

Performance

Objective: The SO establishes the state of cardiac arrest, calls 911 and then correctly applies the disposable defibrillator electrodes (patches).

Test item: Demonstrate the correct placement of electrodes/patches.

Subskill 4:1: Identify the various features of the AED.

Performance

Objective: The SO will accurately identify the overt features of the AED.

Test item: Identify each feature of the AED by labelling or touching.

Subskill 4:2: Operate the AED according to the steps outlined in the manufacturer's manual.

Performance

Objective: The SO lifts the display module and correctly follows the steps displayed on the screen.

Test item: Demonstrate the use of the AED as you would in an arrest situation.

Subskill 4:3 The SO will adhere to the warning messages displayed on the screen of the AED.

Performance

Objective: The SO complies with the caution/warning messages as indicated.

Test item: If the display reads "tape" what does this mean?

Subskill 4:4: Maintain the device to ensure proper functioning at all times.

Performance

Objective: The SO will keep the AED's battery charged at all times to ensure it is always ready for use.

Test item: How many hours does it take to fully recharge the AED's battery?

Instructional Design Plan

The objectives in this guide have been clustered and sequenced to provide a general framework for instruction. The entire session can take approximately half an hour depending on the learning needs of the individual. The objectives are sequenced to foster continuity and enhance learning by building on acquired knowledge and skills through review and practice sessions. Since the subject matter is new to all learners a certain amount of apprehension can be expected. This, however, can be reduced by learner involvement and building of self-confidence when mastery of each skill is achieved.

The session should begin with the instructor introducing him/her self if not already known to the learner. An icebreaker - comment in regards to the patient's and SO's courage can be made to set the climate for the learner. The instructor can explain the purpose of the session and the objectives to be achieved. At this time the patient and SO should be encouraged to express what **their** expectations are. The instructor can elicit from the participants if they know **why** the AED is being offered as an adjunct to the present therapy. The incidence of heart disease and associated risk factors can be explained. This can be followed by explanation of the features of the device. The SO/participant is walked through the various steps of application - from the attachment of the electrodes to the discharging of the machine. The instructor uses a simulator and an AED to demonstrate **how** the AED **actually** works. The instructions are given in accordance with the manufacturer's guidelines and operator's manual. The operator's manual has been evaluated by the investigator (see evaluation section) and found to be appropriate for the literate operator.

Demonstration of an entire session is given followed by a step-by-step review with embedded questions posed to the learner to ensure comprehension. The learner then practises until mastery is achieved. A complete and perfect demonstration in the AED's use is the expected outcome of the session. Maintenance of the equipment is explained and where CPR courses are offered form part of the discussion.

This instructional plan fits well with the model advocated by Knowles (1953) on the principles of adult education which has three distinct sets of needs and goals:-

1. The needs and goals of the individual which are to ultimately realize self-identity through the development of his/her full potential.
2. The needs and goals of the institution - that individual's needs are consistent with the direction it has for them, that institutional operation is improved by individual's effort and public opinion is raised and involvement results.
3. The needs and goals of the society - to have a dynamic populace that can adjust to change and challenge.

The needs and goals are to be met through an instructor-mediated session. A strong emphasis is placed on frequent self-directed review sessions by the SO to promote retention of skills. One method of facilitating learning is to encourage the SO/participant to **teach** the skills to someone else. In this manner the clarity and comprehension of the material/tasks can be assessed. It also helps the SO to build confidence to perform the task in a real situation.

The media chosen to deliver instruction is dependent on the desired outcomes as well as the nature of the teaching/learning situation. The most appropriate method to respond to the needs of the SO in the AED programme is through teacher mediated instruction. Two important factor taken into consideration were: the emotional nature of the problem with its divesting effects if the intervention proved unsuccessful, and the

one-to-one delivery of instruction. In the former the SO must be coached/prepared to make the intervention knowing that even if all the right steps are taken the event could still be unsuccessful. The latter one-to-one delivery of instruction, allows for better identification as well as response to individual needs.

Not only can mastery of learner's performance be assessed, but the opportunity is there for the instructor to encourage, instill confidence and answer questions. Along with this humanistic approach, a video cassette or printed material can later be used to supplement the initial training session.

Printed material which includes the manufacturer's manual as well as coloured diagrams of the heart's conduction system is used in the training session. Illustrations of normal heart rhythm and origins of VT and VF (rhythms that cause cardiac arrest) are shown with appropriate explanations. These teaching aids can be used at the bedside, physician's office or classroom. An informal approach to the session is encouraged to decrease the level of anxiety for the learner.

Strategies

The strategies that will be used in this module are based on Knowles' (1980), principles for adult learners. Principles which foster a participatory and collaborative atmosphere in a teacher-mediated environment. The various strategies outlined below show how specific facets of the proposed instruction should be carried out.

Motivating the learner

Performing a task that is generally designated for trained medical personnel can be very daunting to a lay person. However, when the knowledge to be acquired enables him/her to save a life, it becomes a significant motivating factor. Today many communities encourage lay persons to take CPR training so they can intervene and save a life with these skills. Being able to save a loved one's life may be all that is required to motivate the SO. The use of the AED can be considered a step above the basic CPR skills.

It must be mentioned here that currently most paramedics in the United States are allowed to intervene with the AED. In Quebec ambulances are not equipped with AEDs, nor are ambulance attendants or paramedics covered by law to institute advanced life saving measures. This fact has caused some concerns by the public. Some of the SOs in this study expressed dismay that trained paramedical personnel were prohibited from using the AED, while they as lay persons were allowed to do so. It must be borne in mind that specific medical acts are delegated to some paramedical personnel and to breach this law is considered a criminal offence.

Taking on the responsibility of using the AED on a family member goes along with the concept of instituting CPR in the general public. Within the environs of a health facility, CPR activities still rest with trained personnel even if the family member is present during the arrest.

To sustain interest in the material being taught, the material should be presented in a simplified, well-paced manner. This will also allow for comprehension of the concepts and information. A comfortable non-threatening atmosphere should be maintained where the learner is encouraged to ask questions and not be dismissed or embarrassed when the right answer is not given. An additional strategy is to give immediate feedback during the session. Above all, the instructor should give praise when the learner makes progress. This will help to stimulate interest and build the learner's self-confidence.

Orienting the learner

The SO/participant should be given a copy of the operator's manual to review. At the beginning of the session, the instructor will go over the objectives/tasks the learner is to achieve on completion.

Testing

No formal pre and post tests will be given for the session. Since **mastery** is the key to success in this instance, embedded questions pertaining to **problem-solving** issues will be asked. Accurate **performance** of the tasks is the mandatory requirement.

Information presentation and learner participation

Objective three has been selected to illustrate how information can be presented and how the learner is involved in the training session:

Objective 3: The SO can list centres where CPR courses are given to the public

Information: There has been growing interest among lay persons to be able to intervene in emergency situations both in and outside the home. Various non-medical institutions have responded to these needs by offering courses in First Aid and CPR. Among the centres which give these courses are the school boards in their continuing education programmes, recreational centres like the men and women Y's and also St. John's Ambulance Brigade. Some institutions of higher learning like CEGEPS and universities also offer CPR courses for adults.

Example: The YWCA situated in downtown Montreal and Concordia University Continuing Education Department have seasonal courses in CPR.

Practice session: The instructor allows the SO/participant to operate the device in accordance with the steps outlined on the AED's screen.

Media: Instructor

Closing

The instructor offers suggestions to the learner to help maintain the skills acquired. The SO is encouraged to develop an action plan for review and practice sessions. These sessions should be done on a regular basis until a degree of comfort is achieved by the learner. The frequency of practice can later be reduced as the SO sees fit.

Remediation and enrichment

The SO can better grasp the concepts and depth of the problem by reviewing the operator's manual, reading articles on the topic written specifically for lay persons and by asking questions of physicians and medical personnel. Questioning helps to clarify myths and misconceptions.

Media Selection

The instructor will use the actual AED and the operator's manual to demonstrate the skills. A simulator will be used to simulate the rhythms that can lead to an actual arrest. A coloured poster with illustrations of the heart's conduction system and the site of the death-producing rhythms will be used to make the information more vivid.

Evaluation

One of the most important aspects of any teaching/learning endeavour is to determine if the objectives have been met. In this instance, effective performance by the SO is the desired goal. Several simulations of arrest situations will be conducted until the SO has perfected the necessary skills. Successful performance not only builds confidence in the learner, but can contribute to a successful outcome. In addition to evaluating learner performance, the investigator conducted a formative evaluation on the teaching/learning module. This evaluation is outlined in the subsequent chapter.

CHAPTER 6

EVALUATION - PHASE 3

Dick and Carey (1990) describe formative evaluation as "the process instructors use to obtain data in order to revise their instruction to make it more efficient and effective" (p.234). Emphasis is placed on the collection of data and the revision of the instructional materials based on feedback from the data collected.

In this study, data garnered from the key players in the AED home placement programme formed the basis of the evaluation. Data have been evaluated from three broad perspectives:

- 1) the learners' concerns regarding the effectiveness of instruction prior to an incident and the maintenance of skills following an incident. The learners were both patients and SO's.
- 2) the sponsoring organization whose views here were mirrored through the professional perspectives as given by the programme director, staff cardiologists and cardiology fellows. These groups voiced their knowledge of AED's, the reasons for and concerns about its application.
- 3) the instructional design perspective looked at the analysis of the programme in terms of the behavioural changes of the learner based on Gagné's

taxonomy of learning objectives. An evaluation was made of existing educational materials to assess their adaptability and response to certain types of individual differences. Assessment was also made to see whether the programme indeed speaks appropriately or inappropriately to the key players i.e. whether their needs have been met. The knowledge of the SO was evaluated to gauge the learning curve and the levelling off of knowledge. A subject matter expert assessed the module developed by the investigator. This evaluation aimed at identifying all the principle factors that affected the key players.

Learner Perspective of the Programme

All the SO's in the programme stated they were satisfied with the instructions they received in use of the AED (See Page 60 - 63). However, none of the participants have had the occasion to use the device in an actual event. Due to this fact, performance could not be assessed. There were some participants who voiced a need for a follow-up session.

To date only one participant has been given a follow-up session. This session was conducted by the investigator one year after the initial instruction. It was given in the form of questions and answers to assess any knowledge deficit the SO had. A hands-on demonstration with the AED was used to evaluate the steps in sequencing during a performance. This method allowed the SO to see how much knowledge was actually

retained. At the same time, the investigator was able to pinpoint any weaknesses and make suggestions to enhance retention.

One major concern that was evident from the study was the lack of proper maintenance of the equipment by the SOs. This may be due to the fact that the AED never had to be used. As a consequence, the SO/patient became lax with its upkeep as time passed. Patients and SOs need to be reminded that proper working order of the AED must be ensured if it is to make a difference when it is actually needed. (See Page 65 - 69).

Sponsoring organization - professional perspectives

The programme director has demonstrated a thorough background knowledge of the AED and undoubtedly endorsed its application in a variety of non-clinical settings including the home. (See Page 30 - 32). He has certainly taken a leadership role in bringing the programme to Canada. He has maintained sole responsibility and accountability for the programme and the families involved. His belief in innovation as well as empowering the lay person can best be summed up in Kaufman's (1972) words. "To remain static is to await decay and evolutionary extinction; to react is to risk dissipation of energy without achieving relevancy and to innovate and act to increase our responsiveness to other people is to invite criticism" (p.4). "The key to educational success lies in people, and any process can only be as good as the people who use it" (p.1).

The two staff cardiologists interviewed saw the programme as being worthwhile. One qualified his position by stating that he preferred the device to be used by those with medical knowledge or highly specialized training. He specifically cautioned its use by some para-medical personnel. (See Page 43 - 50). The other cardiologist took a more liberal approach advocating a holistic model of education. This approach would enable the needs of the SO to be addressed from all three learning domains. The affective domain was specifically highlighted because of the emotional implications participants in any home placement programme will have to face. While psychomotor skills can be perfected with practice, the emotional response to a crisis situation is more unpredictable. To decrease the feelings of guilt and blame that the SO might harbour should an intervention prove unsuccessful, preparation for and discussion of such a probability must be thoroughly explored with the SO. The latter cardiologist believed this practice to be embedded in the holistic model.

The views of the three cardiology fellows and their attitudes toward the use of the AED were comparable to those expressed by the staff cardiologists. This group was also not in agreement with the fact that non-trained medical personnel (lay persons) are allowed to use the device. The investigator expected to find a more liberal approach from these younger and more recently graduated professionals. This expectation was based on the fact that the present health care services and resources are strained and are expected to worsen as costs escalate. Consequently, preparing the lay person to share

some of the responsibilities for their own health and participating in care procedures where possible and appropriate seem like reasonable expectations. This expectation was not shared by the fellows or the cardiologists.

The ethical and social issues raised by the group are certainly cause for further study by both professionals and the public. However, as medicine broadens its scope and moves away from an extensive institutionalized system to a more community-based one, then home-care programmes like the AED will be the norm rather than an isolated practice. It has been predicted that more complex/technical procedures may be done in the home and not necessarily by trained health care providers. Instead, lay persons, including relatives and helpers will be given specific types of instructions/training to assist them in carrying out these tasks. The profession of medicine then will have to not only rethink how certain medical procedures are being done and by whom, but medical professionals may be forced to become active participants in such changes. Medicine will not only have to teach but advocate preventative medicine in order to maintain a viable health care system.

Instructional Design Perspective

Using an instructional design perspective, the investigator evaluated both the components of the programme and effectiveness of the instruction. One of the first steps was to evaluate the operator's manual presently being used for its appropriateness and adaptability to different types of learners. The objectives of the manual were clearly

stated. The readability - clarity, sentence structure and polysyllables used were consistent with those required for a grade eight reading level using the Gunning Fog Index. The material was appropriately sequenced and not ambiguous. The manual used pictures and diagrams to illustrate salient points. An added feature was the definition of terms where the components of the AED were identified and explained. Relevant information was also given on how to troubleshoot any problems encountered during operation.

Two disadvantages of the manual were noted. First, it was designed to clearly address the technical aspects of the AED only. Second, no symbols were used, nor was there a voice directed feature built into the AED to guide those with a reading handicap. Both disadvantages made the AED (except in one case) unsuitable to address the needs of different users, e.g. the illiterate or visually impaired etc.

The AED itself has proved reliable from the study's findings. The learners have been able to practise with the device without any incidence of failure. The investigator noted no technical malfunctions during demonstrations.

The delivery of instruction to date has been restricted to the programme director, except in one instance where the investigator gave the instruction. The time factor for giving instruction by the director averaged about an hour. The session with the investigator lasted forty-five minutes, but more visual aids were used for demonstration. The actual hands-on demonstration can take as little as fifteen minutes. The extra time

needed is to build confidence in the learner and answer questions that cover a wide range of possible situations. For the professional users of AEDs, the AHA has devised several algorithms to guide in the application of these advanced techniques in caring for the cardiac arrest victim. However, it has been stressed that algorithms are not recipes to be doggedly applied. It is expected that the professional respondent in any arrest situation will use common sense and therefore be flexible and responsive to the needs of the victim. While algorithms are not part of the repertoire for this group of learners, accurate assessment of the problem must be made to ensure the intervention is appropriate. How to make these assessments is a fundamental part of this learning process.

The learners in the study have all expressed satisfaction with the instructions they received. Since the technical skills required for an intervention should be practised/used regularly if they are to be effective during an event, the investigator conducted a follow-up session one year after the initial instruction to assess the levelling off of skills. The learner's knowledge and ability to use the AED were good. This session allowed for validation of the learner's skills. It also provided the opportunity to examine the need for mandatory follow-up sessions by the users. There is a general recommendation by the AHA and QHA for those who carry CPR certification to take annual refresher courses to ensure adequate skill performance. This stipulation is based on twenty years of research conducted by AHA around CPR skills. For the AED user, having a yearly

refresher course to ensure maintenance of skills and knowledge may also be necessary. This may particularly be true for those in this study since no one has had the occasion to actually use the device.

An important aspect of evaluation is to test the materials being developed on a single learner and revising the materials accordingly. This can make a significant difference in the overall effectiveness of the material (Dick and Carey 1990). In this study no new participants emerged as the programme was being developed. The investigator enlisted the help of the last SO who gave valuable feedback on the module from a learner's perspective.

The SO assessed the module in terms of clarity of ideas, the sequencing of steps to be performed during an event and the general comprehension of the module and its purpose. From this feedback, modifications were made to meet the specified suggestions.

Last, but by no means least, input was obtained from a subject matter expert. The expert is the assistant nurse manager in the coronary care unit who has many years experience in a variety of clinical settings including the last twelve in cardiology and holds Advanced Cardiac Life Support (ACLS) certificate. The assistant nurse manager's role includes teaching new staff members, patients and families. It also includes being a member of the cardiac arrest team for the hospital. Because of her vast knowledge and practical experience with arrest situations, the manager was asked to review and critique

the guide for any discrepancies, lack of clarity in ideas presented and its overall usefulness and appeal. Following review of the package, feedback was give to the investigator both written and verbally. The general comments about the module were that it was well presented and adapted to the needs of the lay person. However, no significant suggestions were made in relation to format or sequence. The assistant nurse manager see the guide as a valuable adjunct to the operator's manual.

It is hoped that as new participants in the AED home placement programme emerge, the module can be further tested and revised as needed so that it can be incorporated into the programme.

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APPENDICES

APPENDIX A

Interview with the Director of the AED Programme

APPENDIX A

Interview with the Director of the Home Placement Programme of the Automatic External Defibrillator (AED).

Initiation

1. What prompted you to institute this programme at the MGH?
2. What is the cost of an AED? Who pays?
3. What is the present status of the programme?
4. How long has the programme been in existence?

Criteria

5. What is the criteria for patient selection?
6. What category of patients gets/has the device?

Education

7. What do you expect patients and SOs to know of the health problem?
8. Explain the details, steps of a training session.
9. Besides training with the AED, what other skills are required by the SO?
10. Are there follow-up sessions to assess retention skills?
11. How is the device maintained?
12. How long is the patient expected to keep the device?
13. What resource persons are available to the patients and families besides you?

14. How are emotional/psychological problems handled?

Responsibility/Accountability

15. Who holds the ultimate responsibility for the programme?

Future Trends

16. Do you foresee an increase in the number of patients with the AED in the home?
17. Under what circumstances can you see the device being used more readily?
18. General comments.

APPENDIX B

Interviews with the Cardiology Fellows

APPENDIX B

Interviews with three cardiology fellows from McGill University

The focus of the interviews was to learn what general knowledge the cardiology fellows had about AEDs and specifically the programme offered at the MGH. Also, to validate the answers questions revolving around the issues of training and education of participants of such a programme.

1. What is your knowledge of AEDs?
2. Are you aware of the programme at the MGH?
3. Under what circumstances would you consider AEDs as an adjunct to therapy for one of your patients? (i.e., what criteria would you use for patient selection?)
4. What issues/concerns do you see or have from this mode of treatment?
5. General comments

APPENDIX C

Interviews with the Cardiologists

APPENDIX C

The focus of these interviews with the staff cardiologists was to ascertain their knowledge about AEDs, their feelings/attitudes regarding the use of this technology by non-medical personnel. The interviews also afforded them the opportunity to voice their concerns about any issues they see arising from the use of the AED outside the hospital setting.

1. Are you familiar with AEDs and their present use by non-medical personnel?
2. Are you willing to use this form of technology in your practice or refer a patient to the programme at the MGH?
3. What training/education do you expect the user of the AED to have?
4. What future trends do you predict for the use of AED's?
5. General comments.

APPENDIX D

Interviews with the Patient and SO

APPENDIX D

In interviewing the client and significant other, questions are directed towards:

1. knowledge of disease process in relation to the use of AEDs.
2. concerns/problems
3. instruction/education
4. recommendations

Patient

1. What do you know about your heart problem?
2. How did you first learn about the AED?
3. What changes did you have to make in your daily living?
4. Were you given instructions in the use of the AED?
5. What general feelings and recommendations do you have regarding the programme.

Significant Other

1. What/how did you first learn about the AED?
2. What kinds of instruction did you receive in the use of the AED?
3. Did you ever have occasion to use the machine apart from the training session?
4. Had you ever dealt with emergencies in the past? What is your usual reaction?

5. Besides instruction and demonstration in the use of the machine what other skills and knowledge did you need to help you cope?
6. Did your lifestyle change drastically during this period?
7. How long were you in the programme?
8. What kinds of resources/support did you have available to you?
9. Would you have benefited from being a member of a support group? How?
10. What recommendations/changes would you make to the:
 - 1) director of the programme
 - 2) to a potential candidate
 - 3) to the instructor
 - 4) to the significant other

APPENDIX E
Schedule of Events

APPENDIX E**Schedule of Events**

April 1993	→	April 1993	→	May 1994	→	June 1994	→	July 1994
Interview with Director		In depth interview with the Director		Interviews with Residents		Interviews with Cardiologists		Interviews with Patients and SOs