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Psychosocial Aspects of Automated External Defibrillator Use in the Home

Author
Rapoport, Lisa N

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Psychosocial Aspects of Automated External Defibrillator Use in the Home

By

Lisa Natali Rapoport

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Committee in charge:

Professor William A. Satariano, Chair
Professor Jeffrey H. Burack
Steven Kegeles
Teresa Picchi

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The thesis of Lisa Natali Rapoport is approved:

William A. Fuhrman	5/16/02
Chair	Date
	5/17/02
	Date
J. Stephen Kapelle	5/14/02
	Date
Teresa Pizelli	5/15/02
	Date

University of California, Berkeley

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Dedication

This paper is dedicated to all poets, intentional or unintentional, some of whose words are hopefully heard in the pages to come.

Acknowledgments

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CHAPTER ONE: INTRODUCTION

Heart disease is America's leading killer, and sudden cardiac arrest (SCA) makes up a large portion of those deaths. Between 250,000-350,000 people per year will experience SCA, and few survive.[1-4] Over 2/3 of those arrests are caused by ventricular fibrillation (VF).[1] VF's etiology is unknown, and the definitive treatment of VF is delivery of an electric shock through the heart muscle, a procedure called defibrillation.

Early defibrillation is believed to be the most critical component in survival of out-of-hospital sudden cardiac arrest (SCA).[5] With the advent of easy-to-use, powerful, and portable automated external defibrillators (AED) defibrillation offers strong hopes of improving the survival of out of hospital SCA.

Because the majority of SCA occurs in private homes, placement of AEDs in the home is a logical idea.[6-8] Early home AED studies, however, showed no increase in survival of out-of-hospital SCA.[9-12] Many possible ideas were put forth as to why this happened, yet no one theory offers a satisfying explanation. The role of psychosocial issues in home AED placement surfaced as it became evident they affected enrollment, a major limitation of these early AED studies.

With this in mind, the question arises if psychosocial effects of AEDs within in the home affect why proper and effective defibrillation might not take place. A few studies began to look at how AEDs in the home affected quality of life, and found that AEDs can have complex psychosocial effects on a home, both

positive and negative. In addition, some couples who receive an AED at home had difficulty adjusting to it.[11]

The limited quantity of research in this area presents an opportunity to ask more questions. For example, with the changing climate surrounding technology and the increased public awareness and acceptance of defibrillation, perhaps the psychosocial effects of an AED in the home will be different from those found 18 years ago. If there are psychosocial effects seen, what are they? Among the many possibilities, couples may report an increase in interpersonal stress, or may indicate an increased level of anxiety surrounding the threat of a future cardiac event. It is important to know how AED recipients feel about the possibility of defibrillation, and if this might correlate with positive or negative survival outcomes. Furthermore, it will be helpful to know which couples would have a harder time adjusting to an AED in their home, and why.

Looking at quality-of-life studies of other technology-driven home interventions helped to further direct research questions. For example, one study found that there was a temporal relationship between the level of stress and a home-placed device: initially stress levels were elevated above non-recipients, but eventually the stress levels declined to below those of the non-recipients.[13] In another example, family members of individuals discharged from the hospital with left ventricular assist devices felt an increase in caretaker burden.[14, 15] Is it possible that such effects occur among recipients of AEDs at home?

This study sought to address these questions, and to begin to provide direction as to how they might be answered. A look at the literature on psychosocial effects of home AED placement will be followed by a review of the literature on psychosocial effects of several other technology-driven devices used in the home, as well as a brief argument for the importance of psychosocial factors in heart disease. Qualitative research methods will be presented, with results ensuing. Results will be presented in 5 categories. The study will then be evaluated as to its limitations. A discussion of the significance of findings, plus questions for further research, will conclude the paper.

CHAPTER TWO: LITERATURE REVIEW

An Introduction to Defibrillation and the Problem of Sudden Cardiac Arrest

History of Defibrillation

Defibrillation, or the passage of an electrical current through the myocardium, has emerged over the last 50 years as the definitive treatment for two specific types of heart arrhythmias, ventricular tachycardia (VT) and ventricular fibrillation (VF). The concept of defibrillation first surfaced in 1775, when Abilgaard described experiments in which he made hens "lifeless" by applying electricity to them, and then could cause a pulse to return by applying a second electrical shock to the chest.[16] It took another 175 years for the first successful defibrillation to take place in humans. In 1947, Claude S. Beck performed the first successful defibrillation on a human. At that time, defibrillation could be performed only by a physician in an operating room, during open heart surgery, because the paddles had to be placed directly on the ventricles of the heart. Furthermore, ventricular fibrillation had to be recognized by visually inspecting the heart.[17]

Nine years later, Dr. Paul Zoll developed the first closed-chest defibrillator. This allowed defibrillation to take place in settings outside of the operating room, and an ECG was used to analyze arrhythmias. However, these early defibrillators were large and cumbersome to use, and required access to a

wall outlet – they used AC current as their source of energy. In the early 1960's it was discovered that DC current could be used to terminate VF more effectively and safely than AC. Defibrillators could then receive energy from stored capacitance, or batteries, allowing them to be portable. As evidence emerged that early defibrillation was successful in treating both VF and VT, physicians began to take defibrillators out of the hospital and into the community. In 1966, the first out-of-hospital defibrillation took place in Belfast by ambulance-transported physicians. Subsequently, traveling CCU (cardiac care units), with defibrillation performed by paramedics, not physicians, became the standard of care for urban Emergency Medical Services (EMS). Then, in the 1980's emergency medical technicians (EMTs) were authorized to perform defibrillation.[16]

In 1993, early defibrillation was formally established as the key to survival of sudden cardiac arrest, and in 1994 the American Heart Association launched a program called Public Access to Defibrillation (PAD) which sought to put defibrillators in the hands of any possible first-responder.[5, 18, 19] A list of possible first responders who are encouraged to be trained to defibrillate by AHA guidelines now includes security guards, flight attendants, central office receptionists, and even family members of high-risk individuals.[20]

Defibrillation has thus progressed from being an extremely technical procedure in the hands of a few highly specialized professionals to a simple procedure that can be performed by laypersons. In fact, one study demonstrated

that naïve 6th graders could be trained well enough to defibrillate that their response times were only 23 seconds longer than trained professionals.[21] Another study showed that defibrillation is easier to learn and perform than cardio-pulmonary resuscitation (CPR).[11]

How has defibrillation become so easy? Several key advances in defibrillation technology have allowed this progression. First, the use of DC current allowed defibrillators to be portable by using batteries as a source of energy.[16] Second, the biphasic waveform was introduced over the traditional monophasic waveform. Unlike the monophasic waveform which is consistent throughout the cycle, a biphasic waveform changes polarity and reverses direction of the current in mid-cycles. Biphasic waveform shocks have shown to be more effective than monophasic waveform shocks of the same level of joules, which allows batteries for storage of energy to be even smaller than before.[22, 23] Additionally, these shocks cause less damage to the myocardium and chest wall.[24] Third, computer chips programmed to detect heart arrhythmias were incorporated into automated external defibrillators (AED), causing new-generation AEDs to be able to "recognize" if delivery of a shock is advised, thereby eliminating the need for an experienced technician to be able to read an ECG. Sensitivity of assessment of VF and VT in these AEDs has been reported at 93-97%, and specificity approaches 99%. In addition, anecdotal and published evidence points to AEDs' mistakes as resulting from human error, such as analyzing a heart rhythm while a body is in motion.[25]

Sudden Cardiac Arrest (SCA) in the United States

The development of AEDs is set against the backdrop of sudden cardiac arrest (SCA). SCA strikes between 250,000 to 350,000 people a year in the United States. Statistics on the survival of SCA paint a grim picture: between 0 and 5 percent of victims of ventricular fibrillation in large urban cities will survive, even if collapse is witnessed.[1, 26] However, this number increases to 15 to 35 percent in mid-sized urban areas with excellent emergency response systems.[27] Whereas zero to 30 percent will survive with administration of defibrillation, under 6 percent will survive if CPR is given alone.[16] Furthermore, one study noted survival percentages doubled if cardiac arrest took place outside the home versus within the home.[6] Thus, survival is dependent on many factors, such as location of collapse, whether the collapse is witnessed, early bystander CPR, early defibrillation, early interface with EMS, and type of EMS system in place.[6, 28, 29]

In an attempt to simplify these many variables, the American Heart Association adopted the term "chain of survival," which refers to the sequence of steps required for optimal outcomes.[30] Many studies in different settings, such as rehabilitative programs, had previously pointed to early defibrillation as critical to survival of VF or VT, and in 1993, Larsen et al. established that early defibrillation is the single most important variable in the "chain of survival" for survival of out-of-hospital SCA.[5, 31] This is reflected in statistics from cities in which EMS has a longer response time on average; in those cities the survival

rates of SCA have not changed much even with the advent and use of modern AEDs.[32] The American Heart Association's Public Access to Defibrillation (PAD) program is therefore appropriately aimed at putting AEDs in quick reach of potential SCAs.[33, 34]

The question that follows, then, is where to put the AEDs to maximize the odds of survival. This depends on where SCA, a population-density phenomenon, is occurring.[35] In spite of the visible number of SCA in public settings, studies show than this constitutes only between 16 to 25 percent of all SCA. In fact, over 80% of SCA occurs in the home.[6, 7] Therefore, placing AEDs in the home is a logical next step, and several studies in the mid-1980's, long before the advent of PAD programs, explored this as an option.

Automated External Defibrillators in the Home: Previous and Current Studies

It is no surprise, given the statistics on SCA incidence and location, that clinical trials exploring home placement of AEDs began early in the history of AEDs. Although these studies did not find that the presence of an AED at home increased survival of at-home SCA, they raised many issues for further study and discussion.

Early Survival Outcome Measures: Dismal Results

As for effect on survival outcome, so far no positive results have been identified. For example, the only randomized controlled trial (Eisenberg et al., 1989) of AED home placement to date had particularly dismal results. Out of a total of 97 participants, there were 14 out-of-hospital cardiac arrests, 10 in the AED group and 4 in the control group. In the AED group, among the 10 cardiac arrests for which the device was available, it was used in 6. Only one of those 6 events resulted in a successful cardioversion, and the patient ultimately sustained debilitating neurologic deficits. In fact, four months after the termination of the study there was only one survivor of SCA, who had been randomized into the CPR group.[9]

Data from Eisenberg's study suggest that the AED was used in 60% of home cardiac arrests. It becomes important to examine what happened to the other 40% of occurrences and if they represent possible barriers to home AED use. Second, these data remind us that not all cardiac arrests or emergencies will be due to ventricular fibrillation (VF) or ventricular tachycardia (VT), the only two rhythms an AED can cardiovert. Eisenberg comments that in order for a home defibrillator to increase survival, it must follow a sequence of events:

> "The home defibrillator must be accepted by the family members and the personal physician; the training must be successfully completed; the arrest of the patient must be witnessed; the arrest must be recognized as an event that requires attachment of the AED; the patient must be in VF; the operator and the AED must perform all operational steps correctly; and the rhythm after the countershock must be a perfusing one" [Eisenberg, 1989 #1].

The reasons for such discouraging results have not been clear, and are very likely due to a complex interaction of many forces. To start, the AEDs used in these studies were older, bulkier, and more difficult to use than the present-generation AEDs. They weighed 35 pounds, and the procedure for integrating defibrillation with CPR was not as simplified as it is today. It is possible that the newer AEDs and their more improved technology could yield better results in a similarly designed randomized controlled study today.[4]

Concrete reasons were also reported, such as unwitnessed arrest in the home, occurrence of an arrhythmia other than VF or VT, and lack of recognition of arrest, causing a family member to not recognize when cardiac arrest was taking place (e.g., fooled by agonal respirations). In one instance a last-minute decision was made not to resuscitate. In another instance, an operator erred such that countershock would not have been provided; fortunately, the victim of collapse was not in VF.[36] Lastly but most definitely significant, these early studies had trouble recruiting subjects, which presents a serious consideration.

Barriers to AED Use in the Home

To expand on this, Moore et al., in 1986, reported that an estimated 53% of all survivors of VF would be eligible and interested in receiving AEDs in their homes, suggesting that approximately half of eligible laypersons would be open to receiving an AED. Yet most studies were not able to yield such a participation

rate. Eisenberg's 1989 study had an enrollment rate of 42% after screening, and McDaniel's 1988 study, although not a randomized controlled study, found 16 patients to receive AEDs out of 213 screened, a 7.5% enrollment rate. The HAT trial, a pilot randomized controlled study testing improved survival outcomes from home AED placement in Oakland, California, is also experiencing limited patient enrollment.[37]

What is causing such small sample sizes in these home AED trials? This could be due to two reasons. First, many specific variables must be in play for a potential subject to be medically or socio-economically eligible. For example, a subject must have survived an uncomplicated myocardial infarction to discharge and would not be eligible for an implantable cardioverter defibrillator (ICD). A potential AED recipient must also have consent from a physician, must be psychologically stable, must live with a domestic partner, and must understand English.

Second, potential subjects might not be interested in participating. This latter reason implicates psychosocial issues as a barrier to home AED use. One early home AED study was able to ask those who declined the AEDs and found that two reasons given were unwillingness to accept responsibility for defibrillation and fear of technology. In another study, denial of the possibility of a second cardiac event also caused couples to chose against the AED at home. Often it was the spouse who refused participation, but themes for refusal between patient and family member were consistent: concerns about health

problems or psychological, philosophical, or religious barriers made home defibrillation undesirable.[9]

Therefore, psychosocial issues arise as possible barriers to AED placement in the home, opening the forum to a more detailed discussion of such issues surrounding AEDs. In addition, this leads to the larger issue of all possible barriers to home AED use. A barrier could be anything from domestic living arrangement, psychological issues, and language, to economic standing.[37] Further assessment in this area is critical.

Psychology of Home AED Placement

Very little has been published on the topic of psychological aspects of home AED use and training. Several of the studies in the 1980s that investigated home placement of AEDs briefly addressed the issue. As previously mentioned, Moore et al. suggested little psychological resistance among layperson users of AEDs.[38] Prior to this, in 1985, Cummins et al. asked AED recipients and their families about the psychological and behavioral effects of AED training and home placement, and concluded that no significant detrimental effects were found when compared to training in CPR alone.[36]

Yet Cummins et al. raised many important issues surrounding home AED placement. They found a mixture of responses to the AED ranging from a sense of security due to having an AED at home to embarrassment over the visibility of such a device in their homes. In addition, they found that denial strongly

hindered many families' acknowledgement of the patient's increased threat of sudden cardiac arrest, to such a degree that in their paper they postulated that denial may present a future barrier to home AED placement.[10] This leads to the question, then, of whether psychosocial issues might affect AED use and thus SCA survival within the home.

McDaniel et al, in 1988, used a scale to attempt to quantify and compare the level of depression and anxiety found in subjects trained to use AEDs at home versus post-myocardial infarction patients who did not receive an AED at home, and found a small decrease in anxiety at home as well as a slight but statistically insignificant decrease in depression.[11] However, two out of 16 families in this study reported an increase in interpersonal stress from the device. This suggests that a certain proportion of families, albeit few, will respond negatively. McDaniel did not explore this finding further, which leaves several questions open for future research: to what did the family attribute the increase in stress? What was the family's baseline level of functioning before receiving the AED, or even before the occurrence of the heart attack? These questions will become the crux of this paper's research.

The Ease of Training Laypersons

Nonetheless, these early studies did confirm the feasibility of training laypersons to use AEDs in the home. Moore et al., 1987, conclude that "most lay persons can learn to operate an AED safely and under simulated conditions

provide defibrillatory shocks an average of eight minutes faster than typical response times of emergency medical technicians.".[39] However, McDaniel indicated that retention of BLS skills (CPR and AED use) was poor in individuals over age 55, necessitating retraining in three month increments. This study also indicated that individuals over age 70 had trouble with the initial skill learning due to the discomfort of using something so foreign and new. Yet the skills found hardest to retain were found to be CPR skills, not defibrillation skills.[40] The procedures of recommended use today in automatic defibrillation are much simpler, allowing operators to focus on defibrillation first, and then CPR, with airway maintenance last. This should facilitate the training of laypersons above and beyond the already encouraging results found by these early studies.[4]

The information about the ease of training was confirmed more than 10 years later by Gundry et al., who compared the ability to use an AED of 6th graders to EMTs and paramedics. Gundry found that the sixth graders took only 23 seconds longer than the professionals to perform defibrillation in a mock cardiac arrest.[21] Although Gundry's study is criticized for being industry-sponsored, and although one recent review article expresses reservation about training laypersons[41], it is now widely accepted that AEDs are easy to use. One could also argue that Riegel looked at regular bystanders, as opposed to family of high-risk individuals, who might have a different or stronger interest in learning BLS skills, and that "generalizing" all types of laypeople together is misleading.

The Psychology of Defibrillation and CPR

Based on the findings of early home AED studies, it appears that in general, family members and patients are comfortable with the technology behind AEDs and are comfortable being in a position of responsibility regarding defibrillation. One anticipates that the presence of AEDs in the home will not have a negative psychological effect on families. Furthermore, current literature reports that it is beneficial for family members to be present during resuscitation efforts.[42-44] Family members who witness in-hospital resuscitation efforts have decreased symptoms of post-traumatic stress disorder and less prolonged grief in comparison to family members who are not allowed to view the code.[43] Yet what are the psychological sequelae when it is the family members themselves who must perform the resuscitation?

The trauma of witnessing a "code" of a loved one cannot be denied.[42] Furthermore, even highly trained professionals who must perform CPR on a loved one can be left doubting their adequacy.[45] One can imagine that in order to be able to defibrillate a loved one, a partner must step out of the emotional role and into one of control and competency. By virtue of changing the way a person relates to another, the possibility of home defibrillation must affect relationships, or the perception of relationships.[46] Therefore home defibrillation could potentially be a difficult or traumatic task both during and after the event.

Delving deeper, studies have documented the unrealistic expectations of survival held by laypersons towards CPR. Whereas in reality only 1%-18% of

CPR attempts are successful (a wide range depending on variables such as if the arrest was witnessed or location of the arrest), the public expects CPR to be successful in 65%-75% of attempts.[47] Television shows depict CPR and defibrillation as not only easier and less gory than in actuality, but Diem et al. report that survival rates on television reach 67%.[48] What is surprising is that personal medical training is also associated with misconceptions of the effectiveness of CPR.[49] This finding relates to family members who might perform CPR; it is possible that family members have a false sense of confidence about performing CPR at home. Murphy et al. describe that the number of elders who would choose to receive CPR was greatly reduced when they were properly informed of the actual probability of survival.[50] Although several of the HAT participants interviewed understand the dismal statistics they were up against, would as many HAT study participants feel comfortable if they knew the true statistics and picture of resuscitation?

It will be important to inform and educate potential home defibrillation and CPR providers of the true statistics regarding resuscitation, so that providers do not have unreal expectations of defibrillation and are not met with extreme disappointment and self-critique in the face of an unsuccessful event. It would be interesting to compare reactions between CPR and defibrillation providers in the AED and CPR group after they perform resuscitation.

Non-traditional Uses of AEDs

While Eisenberg and others had trouble proving increased cardiac arrest survival from AED placement in the home, other data do help to suggest trends and possibilities surrounding home AED use. A recent study of AED use on a major airline showed that AEDs were used successfully as heart monitors to rule out cardiac arrest in a setting where no trained healthcare professional was available.[51] Perhaps more unanticipated uses will be found through HAT and other future research. This review now turns to examining examples of other new medical technologies placed in the home.

Implications of Technology-Driven Interventions in the Home

The use of AEDs in the home speaks to the larger issue of the use of technology-oriented interventions in the home, an ever-increasing trend in our current health care delivery. The implications of this trend are far-reaching. They can extend from increasing patient autonomy and responsibility in management of an individual's care to affecting the coping process of an entire family in regards to an individual's illness. What kind of commentary is being made about the course of our health care system by the increasing use of home interventions? Beyond the feasibility of the technology, how are these home interventions affecting quality of life?

A good place to begin to examine these questions is to look at other examples of technology-driven home interventions in the literature: home sleep

apnea monitors for infants, implantable cardioverter defibrillators (ICD), and left ventricular assist devices (LVAD). While these three devices have different clinical applications and different modes of use, they are similar in that all three are the product of newly-developed technology that allow an individual to live at home in spite of a high-risk of illness. As studies confirm these devices' feasibility, more studies are beginning to ask how they affect quality of life. The following section will use examples of these devices to highlight specific points about their psychosocial effects of home use.

Infant Home Apnea Monitors

Sudden infant death syndrome (SIDS) is the most common cause of death in the United States between the ages of 1 week and 1 year, affecting 1 out of every 500 to 600 live births. The etiology of SIDS is unknown, nor are there any tests available to predict which infant may be affected. However, many infants at risk for SIDS can be identified (experience of a serious apneic episodes, sibling death of SIDS, pregestational age), which suggests that those infants might benefit from a home monitoring device that can signal to parents if the infant experiences a spell of apnea or bradycardia. Proper diagnostic evaluations and appropriate use of home apnea-bradycardia monitoring is indicated for this at-risk population and may reduce their risk of morbidity or mortality.[52] No definitive answers have been reached concerning the efficacy or cost-effectiveness of these devices.[53, 54] However, in spite of their undetermined

clinical efficacy, infant home apnea monitors continue to appear to alert parents to potential SIDS incidents, thereby justifying their presence in the home.[55-58]

Because the post-partum period is already stressful for parents, it is important to gauge how the use of such a device affects parents in their coping during this time. Many studies have addressed this question. Overall, most parents are reassured by the presence of a HAM in the house.[57-62] Fiser, through a survey in 1985, was able to quantify that while the majority of respondents felt some stress due to home monitoring (judged to be minimal to moderate), all respondents favored home monitoring because of the valuable service it provided.[63] Another study compared mothers of monitored babies versus non-monitored babies and found that although the mothers of the monitored group had a slight increase in situational anxiety, there was no statistically significant difference in health hazard between the two groups.[59]

However, several of the same studies that noted positive psychosocial effects also noted the occurrence of negative effects. There were reports of increased strain on relationships such as marital and other sibling-parent relationships, with one study noting a 15% increase in marital strain during the period of monitoring. [62, 63] Stevens found that parents caring for a cardiorespiratory-monitored infant had increased hardship in coping with their situations.[60] Another study found that in comparing monitored versus non-monitored families, although no other significant differences in family life between the two groups were found, case mothers were at an increased risk of

poor health.[64] And yet another comparison between monitor and non-monitor groups found that monitor-group mothers exhibit a greater level of fatigue than non-monitor group mothers.[65]

Because most studies found both positive and negative effects on quality of life, studies began to look at the relationship between the positive and negative findings. On the one hand, although home apnea monitors did indeed cause increased anxiety among parents, it seemed that most parents felt the increased emotional burden was acceptable due to the important role the monitors played in protection of infant life. Furthermore, a temporal association between the two opposite responses emerged: initially anxiety among monitor users was high, in fact, greater than non-monitor users, but then eventually those high levels of anxiety returned to normal.[61, 62, 66] Abendroth neatly explained that, while initially, in the first 3 months of use, families with apnea monitors had increased levels of stress (and thus decreased quality of life) over baseline levels, within 6 months, the apnea monitor groups' levels of distress came way down below baseline, and the control study group's levels of distress rose markedly. The group using the apnea monitors assigned this to using the monitor every night, judged the device as helpful, and consequently feeling more secure in using it.[13]

In most studies there were a few families who experienced high levels of irritability from and distress during the period of monitoring. This then initiates the question of why some families have an overwhelmingly more difficult time

in coping with the apnea monitors, while most others do not. Variables found to predict maladaptive coping were reported to include pre-existing levels of family resources, health locus of control, and a coping style that involved a preference for information under situations of threat.[66, 67] Level of family resources was highly predictive of mood disturbance throughout the study period, while health locus of control beliefs were predictive of changes in mood disturbance over time.[68] Of particular interest was that, rather than variables related to monitor function or health status of the infant, previous family problems and low satisfaction with social support were powerful predictors of poor family functioning.[67] Thus it appears that psychosocial baseline functioning affects coping.

McCaleb in 1996, went into greater detail about the kinds of relationships affected by the home intervention, further establishing that baseline functioning is key in adaptation. Interview results indicate that families who respond positively are high in adaptability and average in cohesion, and that those families perceive themselves as coping adequately. Analysis of the data reveals significant correlations among family functioning scores and coping pattern subscale scores.[69] This study made the connection between a family's level of coping and that family's functioning level, assumed to mean the degree of communication, support, and adaptability within a family to stress. Findings from this study support the importance of understanding the role of family

functioning and coping patterns of families who use technology-driven interventions at home.

Thus, measuring a family's baseline functioning, allows care givers to have an idea about what a family's particular needs might be in the setting of home interventions. In identifying and attempting to meet those needs, a better coping pattern can be sought.[13, 53, 66, 69] This will require "wise assessment" and referral to extra support by physicians and treating teams.[60, 67] This suggests an ability to attenuate the stress of the situation if resources are offered to these families, a theme applicable to all home interventions.

Implantable Cardioverter Defibrillators (ICD)

In the last 15 years, implantable cardioverter defibrillators (ICD) have emerged as significant in the termination of ventricular tachycardia. The ICD is a small electric device with leads placed on the heart that can detect life-threatening cardiac arrythmias and provide electric countershock when these arrhythmias occur. It is considered here because both the technology behind the device and the patient population eligible for the device are very similar to that of home AEDs. As with AEDs, the development of technology behind ICDs has allowed them to be smaller and more effective. One study found them more effective than medical pharmacotherapy.[70] A recent randomized controlled trial found that post-myocardial infarction patients lived longer with ICD

implantation.[71] Yet because of this, they pose a significant barrier to home AED use.

In spite of their success, ICDs do come with negative consequences: they are expensive, require a surgical procedure for implantation, repeated follow-up examinations are necessary, and recipients might need additional hospitalizations for problems with the device such as infection, or broken or dislodged electrodes. ICD's have also been seen to cause emotional distress in patients who receive shocks, and quality of life studies have thus ensued.

In 1995, Dougherty followed ICD recipients for 1 year, and reported that anxiety, depression, anger, and stress levels were higher in both the individuals who received shocks and their families.[72] Bourke et al. described 6 out of 35 patients who developed florid psychiatric problems after experiencing electric countershocks, none of who had premorbid psychiatric dispositions. These 6 patients received shocks in frequency ranging from 2 in 6 months to 111 in 24 hours, yet all incidences of the device firing were deemed medically appropriate. All 6 of these patients exhibited severe symptoms of anxiety surrounding fear of future shocks, which is considered countertherapeutic because anxiety itself is a risk factor for tachyarrhythmias.[73] Herrmann et al., using a standardized assessment of psychological well-being and quality of life, compared ICD patients to other coronary artery disease (CAD) patients without ICDs. They found that in general, ICD patients were found to have less anxiety than the CAD group, yet distress among ICD patients rose with increasing number of

shocks received. Once distress occurred, scores on a quality-of-life subscale declined, and those patients showed less satisfaction with treatment, and more negative feelings towards treatment. They determined that approximately 15% of ICD recipients experience such symptoms. [74]

If such a high number of ICD recipients have detrimental symptoms, then further analysis of the effects of ICDs on quality of life must be addressed. Ocampo, in 2000, wrote about this new patient population living with ICDs: "in these patients, focus is shifting from evaluating the physical response to . . . evaluating the emotional, spiritual, and psychological responses."[75] No one has yet clearly answered why certain individuals and their families experience a worse response to ICDs than others. Interestingly, the Dougherty study found that level of family coping was not significantly different between the two groups.[72] This provides research questions for further studies.

Left Ventricular Assist Devices (LVAD)

Left ventricular assist devices (LVADs) are implantable pumps used to mechanically support a failing heart, providing normal hemodynamics and end-organ perfusion. This is critical for the 400,000 Americans diagnosed yearly with congestive heart failure, of whom approximately 60,000 could benefit from heart transplantation, because only 2500-3000 donor hearts are available yearly for transplant.[76] LVADs are used to "bridge" CHF patients waiting for transplant. Many studies in the last 5 years have demonstrated extremely successful survival

outcomes, which has in turn initiated debate over the possibility of long-term use of LVADs in the place of long-term medical therapy.[77-80] As more recipients of LVADs are discharged to home life, the evaluation of the psychosocial effects of use of these devices in the home in increasingly important to be included in the measure of their utility.

There are both benefits and drawbacks to individuals who receive LVADs. LVADs permit rehabilitation programs which promote physical recovery and strength before transplantation. They also allow a patient to return home and engage in activities not possible with advanced heart failure: gardening, dancing, and even return to work in some cases. This, along with relief of symptoms of heart failure, undoubtedly increases a patient's autonomy and quality of life.[15, 76, 77, 81] Although it still appears that heart transplantation offers the best quality of life, studies demonstrate that patients who receive LVADs are much happier to be home from the hospital and begin to resume their lives, and have a lower index of depression and anxiety than medically-treated patients awaiting transplantation.[14, 15, 77, 81-84]

However, increased burden of responsibility from management of this new, complicated and highly-technologic device at home has emerged as a significant negative consequence on quality of life. Grady et al. reported that patients expressed significantly more self-care disability, and two other studies reported an increase in family caregiver burden.[14, 15, 81] This was attributed to patients' (and likely families' as well) perception of "an inability to care for

themselves after LVAD implantation."[81] To counter this outcome the suggestion was made for providing psychosocial support through educational programs, counseling, and mentoring programs. This will help patients and their families to manage this device yet not allow them to feel abandoned with the new responsibility.

Extrapolations to Home AED Use

Many of the themes brought up by use of home infant apnea monitors, implantable cardioverter defibrillators, and left ventricular assist devices can be applied towards the use of automated external defibrillators (AED) at home. The increase in patient autonomy – that is, permitting a patient to return home – is argued to be one of the greatest benefits to quality of life provided by use of home interventions. Indeed, all of the interventions reviewed supported this theory, demonstrating that the return home to attempt to resume normal family life is extremely beneficial. An AED at home could do the same, augment a patient's autonomy and provide increased mobility. For example, it can allow an individual to stay at home while waiting for ICD implantation.

Another theme that emerged was that of mixed positive and negative effects on quality of life but with the net result that the device provided reassurance and increased psychological comfort to the individual and family. This was seen most clearly in the literature on home apnea monitors and LVADs, where in spite of increased stress attributed to the device most recipients felt

reassured by its presence and would use it again if given the choice.[15, 58, 61] It is very likely that an AED could have this effect, causing both positive and negative psychosocial effects, cumulatively balancing in favor of increased benefits. An AED could provide psychological reassurance by allowing a couple to feel some small amount of control over the potential of a frightening event. An AED could also give an individual confidence to resume activities at home that are associated with fear of another heart attack, such as sexual activities.

The temporal relationship of stress attributed to a device followed a pattern of initial increase above baseline with an eventual lowering of stress levels below baseline for the longer duration. Most likely the presence of an AED in the home will also follow this timeline, with much less anxiety surrounding the device as a family adjusts to its presence in the house and adjusts to the idea of having a very concrete plan with which to cope with an emergency of a loved one. This pattern could be as much a part of living with a new technology as it could be a reflection on how a person adapts to a new state of illness, such as heart disease.

Review of the literature on home devices also found significant mention of an increase in caregiver burden. This is very applicable to the use of an AED because it is the caregiver that would have to defibrillate. Although, in couples where each member might be equally at risk for sudden cardiac arrest, there is the possibility of each one having to defibrillate the other, it is more likely for a couple to receive the device because of one member's increased risk or history of

myocardial infarction, thereby placing most of the responsibility for training and management on the other, the caretaker.

However, the examples of caretaker burden illustrated by LVADs and home apnea monitors may not entirely predict home AED issues, because typically an LVAD recipient is much more ill than a home AED recipient. In addition, the relationship between patients and the device is different in each group. One can easily place an AED in a part of the home and forget it is there, whereas one cannot forget the presence of an LVAD due to the extracorporeal component of the device. Furthermore, an infant that requires constant monitoring has a much greater level of dependence on the caretaker than an adult member of a domestic couple.

Nevertheless, why might families be experiencing increased caregiver burden? One might consider the fact that an ill family member – one who would be so ill that formerly would not have been discharged home – is now home and needs taking care of. Benefits of the trend of increasing use of home technology-driven devices are evident: reduction in cost of expensive hospital stays, and increased patient autonomy, quality of life, and survival, in some cases. Yet at what costs do these benefits come? Is the onus of care of ill patients being displaced from hospitals to families?

The review of ICDs brought up the issue of anxiety surrounding an uncontrollable threat. ICD patients who had already received painful shocks to terminate arrhythmias experienced greatly elevated levels of anxiety

surrounding the possibility of receiving another shock. Part of this anxiety surrounded lack of control over when and where this might happen. It is conceivable that AED recipients (and their caretakers) might also experience a mild form of this anxiety, knowing they are at risk for another MI but not knowing when or where it might occur. However, this anxiety, if present, would be difficult to separate out from anxiety felt by all individuals at risk for a second MI, not just AED recipients. Arguably, an AED might help to reduce that anxiety by providing a means or sense of control over the threat.

The last theme to emerge from review of these examples is that of identifying why some families cope poorly with having these devices at home. This was clearly addressed by several home apnea monitor studies which documented that the strongest predictors of mood disturbance for families were neither the severity of their child's risk nor device-related variables, but rather a family's pre-existing levels of resources, locus of control, health beliefs, and coping styles, previous problems, and low satisfaction with support.[66-68] Furthermore, families who described themselves as coping well ranked high in adaptability and average in cohesion, and there were significant correlations between overall level of family functioning and their ability to cope with the device at home.[69] Therefore, one can gauge that it is a family's baseline functioning that is important in coping with a technology-driven device in the home. This pattern parallels a similar level of coping with sudden onset of illness, in that how a family responds to a traumatic event such as sudden

cardiac arrest, will also reflect that family's baseline functioning status. These themes are obviously highly applicable to home AED use.

Family as an Arena for Therapy

Providing psychosocial support was raised within all three examples as a means to help prevent or attenuate families' negative responses to home devices. Although all families will need social support, it is important to identify which families might need additional help adjusting. Not allowing families to be abandoned without psychosocial support is of huge importance when one considers the interrelatedness of families, illness, and coping. [72,75 85]

Furthermore, family stress scores have been reported as stronger predictors for negative outcomes of illness than other stress scores such as social stress and support variables. Patients with a high level of self-reported family stress had lower quality of life, lower functional health, and lower social support scores, combined with high dysfunctional health and social stress scores than patients without a high level of family stress. [86] Therefore, even perceived stress is a predictive variable in a family's coping, and not only will interventions affect a family's quality of life, but families' coping styles can affect the outcomes of interventions. The family then emerges as an important context in which illnesses are played out; it is an arena which both provides caregiving and needs caregiving.

Home Interventions and the Relationship Between Humans, Medicine, and Technology

Lack of understanding regarding a medical condition, fear of technology behind a device, and lack of adequate medical education have all been named as reasons for refusing or lack of compliance with a technology-driven device at home.[87] On the other hand, a feeling of needing the device for survival, trust of medical technology, and reassurance provided by the device have all been named as reasons for continuing use.[58, 59, 84] Furthermore, not fully understanding clinical outcomes due to a device or its use could affect an individual's choice to use or not use it, as is seen when individuals request full code status when it is not in their best interest for quality of life.[88] Many of these themes are dictated by an individual's personal relationship to medicine and medical technology. This is a hugely complex topic, which varies by individual and by device. Although not covered in this paper, it deserves mention as an important variable in how an individual and family accept or cope with a device in their home. This review will now focus on the relationship between psychosocial variables and heart disease.

The Importance of Psychosocial Factors to Heart Disease

Previous home AED studies have noted but not fully explored the relevance of psychosocial factors to home AED use. Review of the literature has also shown that psychosocial issues are important factors in the use of health

technologies at home. What ensues in the following is a brief discussion of that relationship between psychology and coronary heart disease, and how an AED might play into it.

What is a psychosocial factor, and how does it affect a cardiac event?

Much data has been published on the relationship between coronary heart disease, myocardial infarction, and psychosocial factors. Perhaps a good way to start approaching this topic is to define what is a psychosocial factor, and how one might affect disease. In 1999 Hemingway and Marmot defined a psychosocial factor as "a measurement that potentially relates psychological phenomena to the social environment and to pathophysiological changes."[89]. Psychosocial factors may act alone on an individual or combine in clusters, and their effects may have different significances at different stages of life.[90] Examples of psychosocial factors include psychological traits (such as type A behavior and hostility), psychological states (such as depression and anxiety), psychological interaction within work (as in the relation of job control and demands to job support), and social networks and social support.[89-97]

The Importance of Mood On Risks and Recovery of a Cardiac Event

There have been countless articles examining the relationship of psychologic states to the risks and recovery of a cardiac event. This section briefly scratches the surface of the matter.

Depression has been strongly implicated in heart disease. Januzzi et al. found that both anxiety and depression wielded a "graded" risk over the development of coronary artery disease.[98] One study indicated depression as a more powerful and independent predictor of cardiac mortality than any other measurement of risk after the control of variables such as left ventricular dysfunction, tobacco use, or prior history of MI.[89] Another study found depression itself to be a sentinel for cardiac event.[99] Depression alone has also been documented by many studies to negatively affect prognosis after myocardial infarction.[89, 96, 100, 101]

Emotional distress and anxiety have been increasingly recognized as important risk factors in a patient's prognosis after myocardial infarction.[94, 102, 103] Anxiety early after myocardial infarction is associated with increased risk of ischemic and arrhythmic complications.[104, 105] Januzzi et al. noted a correlation between a specific type of anxiety, phobic anxiety, and a 6-fold increase of risk for Sudden Cardiac Arrest (SCA). [98] The "Global Utilization of Streptokinase and Tissue Plasminogen Activator for Occluded Coronary Arteries" (GUSTO) study found a 2.5- to 5-fold increases in risk for ischemic complications or reinfarction have been found in patients with high levels of anxiety when compared to patients without high levels of anxiety.[106]

Another psychosocial variable, denial after myocardial infarction, has been found to be linked to prognosis in a two-pronged pattern. In the initial post-MI recovery period denial facilitates adjustment to a new state of ill

health.[107] However, long-term denial correlates with poor prognosis after MI, because patients disregard symptoms of forthcoming cardiac events and fail to seek and comply with rehabilitation regimens.[106] What becomes increasingly interesting is that another complex pattern of denial exists when patients face the trauma of a cardiac event. Referred to as "approach coping" by van Elderen et al., the emotional and cognitive processing of an MI is associated with increased emotional distress in the short term and decreased distress in the long term.[108]

Social support also plays an important role. Increased social isolation has found to be linked to increased incidence of coronary artery disease.[109] Hemingway and Marmot found that in 9/10 studies reviewed for that purpose, social support proved an important prognosticator.[89] Frasure-Smith et al. found that depression after an MI is indeed a predictor of cardiac mortality, however, that negative effect can be "buffered" by social support.[110] Lane and Carroll found that living alone was associated with poorer post-myocardial infarction prognosis, and that social support decreased stress and increased physical recovery in the time period following a cardiac event.[106]

However, the causality versus consequence of psychosocial factors in regards to heart disease remain something of a circular debate. Hemingway and Marmot attempted to control for these variables in their selection of articles for review, and found that although psychosocial work characteristics are heavily linked to the development of coronary heart disease, evidence shows that depression and social support are independent etiological and prognostic factors

for coronary heart disease.[89] Therefore, a psychosocial factor can be both a cause and an effect on coronary heart disease.

Prognosis and Psychosocial Interventions

Due to the overwhelming data that supports the relation between mood and prognosis, the consensus is that post-MI interventions geared towards individual psychosocial needs are important to recovery and quality of life. Horgan et al. found that psychologic distress after a cardiac event is associated with mortality, quality of life among survivors, and a patient's ability to maintain compliance with a new health regimen. The likely sequela of this concept is that post-MI rehabilitative programs should address and include patients' and their families' "psychosocial needs."[111] In their 1996 meta-analysis, Linden et al. found that psychosocial interventions are associated with improved survival after myocardial infarction.[112] Lane and Carroll also found "compelling reasons for inclusion of psychologic skills within coronary heart disease rehabilitation."[106] Although some studies did not find that psychologic interventions aided in recovery, they have been criticized for using methodology that might cause participants to conceive of themselves as very ill.[113, 114]

Not only has it been found useful to address patients' emotional needs following a cardiac event, but treating the family as well has been identified with better healing and prognosis. In one 1990 study, wives of survivors of myocardial infarction responded to counseling with decreased levels of anxiety.[85]

This is especially important when considering that family stress scores as a strong predictor of poor prognosis.[86] Furthermore, patients with high levels of self-reported family stress had decreased quality of life, functional health, and social support scores than other patients. Therefore even a family's perceived level of stress is important in recovery from a cardiac event.[86] This becomes especially important when family members become primary caregivers after hospital discharge.

In sum, evaluating the complex interreladtedness between AEDs and a myriad of psychosocial factors, some discussed in this section and some not, becomes important in judging their usefulness in patients of MI and their families. Thus, further research in the arena of psychosocial effects of home use of AEDs can be of great value. This paper will now turn to presentation of the research study behind the thesis project.

CHAPTER THREE: METHODS

Qualitative research methods, and specifically, semi-structured ethnographic interviews, offer an excellent way to collect information about an individual's experience. Qualitative methods are particularly useful as there are not much data available in the literature about individual's personal experiences with an AED at home, and interviewing allows for new themes and concepts that might not yet be conceived to emerge. A semi-structured interview consists of a few open-ended questions to prompt interviewees to speak about their experiences. The structure of the interview was based on review of the literature of both AEDs and other technology-driven interventions in the home. The interview was designed to gather information regarding psychosocial aspects of home AED use, as well as to discuss other issues regarding heart disease, defibrillation, and CPR, if they might arise.

Subjects for interview were found through the "Home AED Trial" (HAT), a pilot study run by Kaiser Division of Research in Oakland, CA. HAT is a randomized controlled trial that compares survival outcomes between AED placement and CPR training alone in private homes. All subjects are members of Kaiser who have experienced a full-wall thickness or "Q-wave" myocardial infarction and who live with a domestic partner. There are 20 couples currently enrolled in HAT. This study interviewed each member of the couple separately

for approximately 45 minutes. Interviews were conducted at the Kaiser DOR premises.

Study protocols, interview structure, and consent forms were approved by the Institutional Review Board of Kaiser Division of Research and UC Berkeley's Committee for the Protection of Human Subjects. Because Lisa Rapoport is not a Kaiser researcher, Steven Sidney, MD, was named as co-investigator and Kaiser sponsor.

Telephone contact of interviewees was made by Teresa Picchi, HAT Research Coordinator, to establish permission to be contacted by Lisa Rapoport. The consent document was mailed to participants' homes in advance of their interview, and informed consent was obtained prior to commencement of interviewing on-site. Subjects were identified by a coding system so as to preserve confidentiality.

Interviews were taped, transcribed, and then reviewed for themes. Themes were coded using the program Ethnograph v5. Subjects and their interviews were described in transcripts as either male or female, patient or spouse, and from the AED or CPR group. Two extra readers were asked to review the transcripts to guarantee consistency of themes and to ensure that unanticipated themes had not been overlooked.[112] Interviews were repeatedly re-examined to ascertain if newly emerged themes were applicable to previously reviewed interviews.

CHAPTER FOUR: FINDINGS

Participation

Out of 20 total couples enrolled in HAT, 12 couples gave permission to be called for invitation to participate in this study. Of those 12 couples, 7 declined the invitation to participate, and 5 accepted. Reasons cited for non-participation were refusal or non-interest, such as not wanting to "discuss stress," traveling out of town for an extended period of time, and physical inability to participate (one woman had broken her hip and was in a skilled nursing facility). Most of the 20 were, however, simply did not call back, which suggests lack of interest in participating.

Of the 5 couples that participated, 3 couples were from the AED group, and 2 couples were from the CPR group. In 4 couples the patient was male, and in 1 couple the patient was female. All couples had been married for over 15 years, and 3 couples had been married for over 30 years. Four couples had raised children together. For 2 couples it was their second marriage. All couples were white, and the age range of participants was 56-82 years of age.

Recurrent themes were divided into 5 categories: 1) Similarities between AED and CPR group, 2) Themes of the AED group, 3) Themes of the CPR group, 4) Characteristics of couples with increased anxiety, and 5) Unanticipated themes. They will be presented in that order.

Category One: Similarities Between AED and CPR Group

Overall, the two groups were similar in anxiety levels and quality of life. Specifically, there were low levels of anxiety in both groups, and most couples felt that quality of life had been mildly increased by participation in HAT. All HAT subjects were pleased to be in the study and felt reassured by knowledge of CPR or defibrillation in case of an emergency at home. When anxiety did arise, it did so evenly between both groups, and surrounded performance during an emergency and the threat of another cardiac event. When dissatisfaction or decreased quality of life arose, it surrounded the general issue of being ill, either from heart disease or other co-morbidities.

The couples in each group had similar coping mechanisms to deal with the anxiety surrounding possible defibrillation or CPR. The "que sera sera" philosophy, or, leaving the ultimate control of an emergency up to fate, was prevalent. Self-forgiveness was also expressed, in the form of "do the best you can." A rational approach was also used, such as clearly stating the low odds of survival, or separating the spiritual from the physical in dealing with the possible trauma of having to defibrillate a loved one. Also very significant was the use of humor to diffuse an emotionally tense situation: one male patient referred to his AED as "the bomb in the closet." Another male spouse referred to the vision of his spouse in cardiac arrest as "my sweet bubba on the floor."

Two couples, one from each group, did stand out as having increased levels of anxiety over the other couples. This confirms the idea that some

couples will express more concern in adjusting to this type of situation. To attempt to answer why a couple might have trouble, the characteristics of these two couples were analyzed for commonalities and are discussed in a separate section.

Category Two: Themes of the AED Group

The AED recipients were, on the whole, very happy to have them. In fact, several participants mentioned that they would have been disappointed if they had not received the AED. The AED was referred to either positively - "exotic toy," "lucky rabbit's foot" -- or in neutral tones, such as "out of sight, out of mind." Most participants felt having the AED in the home had changed neither their stress levels surrounding heart disease nor their functioning with their partner. As exemplified by one male patient:

> The machine itself…is...a total plus. And I think [my wife] probably feels about it that way. If it has any minus at all, it's just where to put it and, well, what if something happened and it was…we weren't here or it wasn't there or whatever, [we'd] say, 'That's it, don't worry about it.' And so…it hasn't changed our life in any sense of the word.

The next quote, taken from a female spouse reiterates the previous quote:

> I don't see where the machine has really helped us or changed anything. I think it's nice to know that it's there. You know, it's great…When they said, do we want to participate, do you want to take it, Sure, why not, you know? If something happens and we're in the right place…And if it's not, then you're no better off than . . .

One male spouse spoke to his low levels of worry about having and possibly using the AED:

> Am I prepared to [defibrillate]?...We'll do the best we can...I don't see it as any major problem. I guess we'll cross that bridge if and when we come to it. It's really in the background. It's wallpaper.

Another woman, a spouse, felt relief at how easy the AED is to use:

> The machine itself is so self-explanatory in how to do everything. And I do like the idea...that you can hook it up and if the person doesn't need it, it doesn't do anything.

Mixed Reassurance and Doubt

However, the most dominant feeling surrounding having an AED at home was a mixture of reassurance and doubt. Said one male spouse:

> It's sort of like a parachute, you don't know if it's going to open, but you feel better having it.

Another male patient said:

> Look what they gave me. You know, hey, I won, you know, finally, something. It's worth $3500. And [it'll] probably just never get used, put it up in the closet. I think it would do better if we put it on a fire truck somewhere. [Laughter].

One female spouse expressed considerable doubt at whether the AED could have helped during her husband's first cardiac event:

> The machine seems like a very good machine. And I'm amazed at how it works. It's just [sigh] it's kind of like everything would have to be in

> place. I'd have to be there . . . and have to be aware of that it was happening. And able to get the machine, and use it. But so often we're not there. We're away from home. Or we're not together. If we'd had a machine and things had gone like they usually go within our house, I'd [have] been asleep after he'd come home from walking [the dog]. And he would have sat there and gone, 'Oh, I don't know if I'm feeling [good] . . .And if he had just gone into [cardiac arrest], I wouldn't have awakened, and there he'd be. . . I hear there's plenty about people waking up and they've got this dead spouse next to 'em.

Many participants expressed criticism about the impracticality of having an AED at home beyond simply having to be in the right place at the right time. They stated that having the AED would neither change their activities of daily living nor their travel plans because carrying the AED around is not realistic. In one couple, each member commented about this:

> We've thought about taking it with us...well , in fact, it recommends that you might take it with you...if you were going for any length of time. But we've only gone for, like, a weekend...we didn't feel it necessary to take it. And we wouldn't want it to get lost or stolen. It's not something you'd want to leave in a motel room.

> I'm not going to have somebody carry the AED with me. Maybe if we went away for a week or something, I might take it. But other than that, we go up to visit the kids, and I forget it's even there. Much less take it with me.

Varied Confidence About Correct Usage

Confidence levels regarding the ability to defibrillate were varied. One male spouse said, "I've watched the thing often enough to know exactly what to do." He went on to say, "You've got to do this mechanical thing to sort of get the ... plumbing going again ... which is sort of separate from the person you love ...

To me, that's just mechanics." However, others expressed nervousness about the possibility. This quote comes from a female spouse:

> I think one thing that does worry me a little bit it's one of those, if I get too close to the edge or something, will I jump off? If I would be shocking him, will I get far enough away? Or will I suddenly touch him, you know?

The next quote comes from a male spouse, who described his confidence level as "50-50":

> They've got the machine set up so that it's very informative, but it's just not something you do every day. . . and you can't [practice with] the paddles,. . . to me it kind of leaves a little bit of guesswork there.

This lack of confidence was also directed towards the idea of being defibrillated. One female patient expressed lack of confidence in her husband's ability to defibrillate her:

> I had a discussion with my husband about...his reaction time...You know, they got the steps...You check to see if they're breathing, you check to see if they got a pulse, and then you go and get the kit and then you call 911, and then you go open the door and all this jazz. And I thought, holy cow. All of this stuff to remember...and especially with somebody that you're attached to, emotionally attached to. So I said, 'You know, let's simplify this thing. If I'm lying on the floor unconscious,' I said, 'Call 911, open the door, and slap the damn thing on me.'

Note the use of humor as means of coping with this anxiety in this quote. In addition, several couples also mentioned the idea that the patient might one day have to defibrillate the spouse, although this was not a consistent theme throughout the couples interviewed.

AEDs and the Home Environment

Two interesting themes regarding interaction between AEDs and the home environment emerged: first, where to place the AED, and second, defibrillation of neighbors. Most couples discussed where they should store the AED. It was difficult to find a place that was perfectly suited. On the one hand it should be kept in an accessible place where it would not be lost, forgotten or damaged. As one male spouse said:

> It's been long enough that you kind of forget about it, you know?...We had it in a kind of unobtrusive place, which you don't want it in...in a place where it's subject to damage.

Another male patient described losing the training tape:

> I took [the AED] home, put it in the closet and it's been in the closet. I watched the tape once, and in fact, [I'm] kind of embarrassed, today, we looked for the tape and I can't find [it].

Yet, on the other hand, discussion also surrounded putting the AED in a place where it is most likely to be needed. One member of a gay male couple mentioned that there were actually two houses on the property, and deciding where to put the AED was tricky:

> In the closet in the bedroom, on a little shelf there. I figure that's were we're most likely to be... Actually, we have two little houses, and like everything in our life it's not normal... There are times when we're not in actually the same house, we're 30 feet away. Most of the time we're in the front house, because that's where we sleep... We're between these two poles... It's possible he could have a heart attack in the back house and I wouldn't know it.

Another female patient spoke about the discussion process:

> It's in our ... dining room/family room combination. I've made a special place for [the AED], so that it's just about this height, they can grab it fast and ... whoever should need it. I kind of made the decision...I said, 'You know, we've got to put this...' He agreed that we needed [it] to be in an accessible place. I said this was a place where everybody'll see it.

AED recipients voiced in general that they were comfortable with the idea of defibrillating a neighbor. Mostly this was born of the feeling that the AED could be more useful if it were applied to a larger population. One couple, however, discussed whether or not to tell the neighbors that they had an AED in their home. They decided against it:

> We decided against telling the neighbors we had it, because we both agreed that...if the neighbors knew we had it, somehow inexorably we'd feel some responsibility...to be there, hang around the house. We just sort of felt that that would...that would add a little strain of anxiety to the relationship with the neighbors.

> If I thought I was going to have to use it on a neighbor, I would worry that something bad would happen...And that would bother me. Whereas [my spouse] is free to experiment on me...We trust each other to do our best in that relationship, where I wouldn't feel that way quite with a neighbor...I mean, you can't experiment on a neighbor.

These quotes are suggestive of the characteristics of a relationship that might be necessary to withstand the possibility of defibrillation. Because defibrillation is still seen as both experimental and a source of extra responsibility, a relationship that can tolerate the idea of it must have a certain level of intimacy, trust, acceptance, and forgiveness. If a relationship does not have these qualities, the idea of defibrillation could cause anxiety or tension.

Category Three: Themes from the CPR Group

The themes of the CPR group did not differ significantly from the themes of the AED group. Two couples were in the CPR group, making a total of 4 interviews. Both patients were males, and both patients had significant co-morbidities. All four individuals felt that CPR was very useful to know, and felt moderately confident about administering it. However, both female spouses expressed lack of confidence in their ability to move their husbands' bodies to flat surface to perform chest compressions if need be. Yet in keeping with similarities found among both groups, this mirrors the concern voiced by one AED recipient who also worried about the possibility of moving her husband's body.

Category Four: Characteristics of 2 Couples with Increased Anxiety

Two couples, one in each group, were found to have considerable anxiety. Although this anxiety included apprehension about the possibility of defibrillation or performing CPR, it reflected a general difficulty around living with heart disease and the threat of another cardiac event. The four interviews from these couples were re-examined to look for common themes that were not as prominent in the other interviews. Three commonalities were found: a lower level of baseline functioning, lower social support, and a more traumatic first cardiac event.

Baseline functioning refers to a couple's ability to relate to one another and manage stress before the AED or CPR training arrived into the home. That is to say, any stress caused by an AED or CPR training is going to be a reflection of how a couple handled stress either before receiving the AED or CPR training or before the onset of cardiac disease. For example, for one couple, it seems that the cardiac event and the ensuing depression of each individual had pushed the couple into couples therapy. For the other couple, their ability to relate to each other regarding illness was low even before the onset of cardiac disease:

> I'm not very patient with it. He does a lot of touching his chest, which is irritating to me...We've always had trouble around illness. We do not connect well around illness. He kind of wants me to do more caring, be caring for him more than I am able to do... It's been not a whole lot different than we've had around other illnesses.

This same female spouse spoke about their relationship after the onset of her husband's cardiac disease:

> When he woke up, I [said], 'This is really something. You have a chance, this is like one of those life changing experiences. You know, you can kind of examine how you've been leading your life. And maybe we could make some changes. Maybe we can really get together and, you know, do things.' [And he said], 'Are you crazy? Why would I want to change anything? I'm fine, happy.' So.

This lower baseline functioning is in direct contrast with the couple that expressed the least worry over adjusting to life with heart disease:

> We talk so much...And when this [AED] becomes something big, we'll have something else to talk about. We get irritated at one another, we get irritated at life. And we just talk, we just talk...There's always some kind of compromise possible.

> When we were first together,...the first five years of the relationship was spent...what we call creating the constitution of the relationship...You sort of say, 'Okay, what kind of relationship is this going to be? And how are we going to be with each other?'

However, assessment of baseline functioning was contingent on how the researcher judged relationship functioning from within her cultural and educational construct, not from quantitative psychometric scales.

Both couples with higher anxiety also exhibited lower levels of social support as compared with other couples interviewed. One couple were both vegans and were very active within their community. However, the spouse (female) mentioned that within their community having a myocardial infarction represented some sort of anomaly:

> You know, within our community of [vegans], you know, having heart attacks...It's kind of saying, well...because people say, 'How did that happen to you?' You know, if you're eating right, how did that happen?

This can be speculated to result in decreased community support on two levels: One, a cardiac event engenders question of the victim's diet and espousal of a vegan lifestyle. Two, the presence of heart disease in a community who believes themselves immune to such problems poses a threat to that community's belief system.

Decreased support on an individual basis, as part of an individual's psychologic disposition, was mentioned by the female spouse of the other, non-vegan couple:

> I'm the type of person who is...not very open...And...I say I can take care of things by myself... People kept asking me, how are you doing, how are you doing? I said, 'I'm fine, I'm fine.' When I don't know that I was. And even, I really didn't say a lot to [my therapist] about what was happening and what I was going through.

Therefore, decreased social support, either perceived or real, can happen at both a community and an individual level. This theme fits well with literature published on social support, mood, and prognosis.

Lastly, these two couples were similar regarding the circumstances surrounding the first cardiac event. Specifically, each had increased emotional trauma. Either SCA had occurred, which is both physically and emotionally traumatic, or EMS had been used to transport the patient to the hospital -- a scene in which one can imagine the loss of control of both patient and spouse as paramedics whisk the patient away. In one of the couples with increased anxiety, the patient experienced cardiac arrest once he arrived at the emergency room. His spouse attempts to make sense of her husband's response to the experience in this quote:

> Just the fact that he was in the emergency room there, that they could immediately ... they had brought him [in], were getting him down the gurney and he collapsed. And they said if he'd been anywhere else, you know, he would have been dead. Because he had just come back from walking the dog when all of this stuff started for him. So, I mean, he could have been ... it could have happened ... been dead on the side of the street. And that is something now that I think is hard for him. He feels nervous being alone.

The spouse of the other couple mentioned not wanting to deal with the possibility of doing CPR if an event should happen again, because her experience with calling 911 and interfacing with paramedics had been so stressful.

It is worth mentioning that the patient-members of these couples did not both have increased levels of co-morbidity as compared with the patients of other couples. There was an increased level of caretaker burden felt by the spouses in these two couples, however, it was not possible to tease this finding apart from the finding of increased anxiety regarding adjustment to living with heart disease.

Category Five: Unanticipated Themes

Four unanticipated themes emerged and will be addressed in this section: 1) the question of retention of training, 2) caretaker stress, 3) the prevalence of depression among patients, and 4) non-classical presentations of myocardial infarction.

Most to all interviewees had reviewed their training tapes the day before coming in to be interviewed, and subsequently were able to recite the steps of CPR or defibrillation accurately and in some detail. However, some interviewees did not remember first watching the video upon their enrollment into HAT. The question must be asked, then, of how much participants retain of the information given in the video. One early home AED study did address this question and

found that defibrillation is easier to learn and remember than CPR. However, for the HAT population, the answer to this question remains to be seen.

Depression was prevalent among the survivors of myocardial infarction. Two of the five patients were suicidal at one point. This is consistent with literature on recovery from cardiac events. Regarding the theme of caretaker stress and depression, it is not surprising that most spouses interviewed had an extremely difficult time during the initial acute illness and recovery period. However, what is surprising is that spouses seemed to have a more difficult time during this period than patients. For example, one female spouse described her exhaustion as being at the upper limit of tolerable:

> When he first came home, he was up every 10 to 15 minutes, I would be up with him. He couldn't stay in bed, sometimes he didn't know where he was. So I was just up and down and up and down...I'd just fall on top of his bed and go to sleep, I'd wake up, put him back to bed. So that first week, I don't know how I got through the first week.

Another female patient described hearing about her husband's difficulties while she was in the hospital from their children:

> I...talked to the kids and heard how upset he was. I know he wasn't...he wasn't really recognizing his reaction, he was really, really upset with the kids. And they recognized [it], and finally two of 'em got on the phone and called his doctor and said, 'He's got to have some medicine. He's not sleeping and he's terrible to be with.'

What is interesting to consider is whether increased caretaker stress reflects a difference between patient and spouse in trauma of experiencing the event, or rather a difference in recalling the event. It is plausible that patients were so ill

that at the time they were not fully aware of their circumstances, or that the event is not remembered in great detail.

The other finding - considered surprising by the researcher, an inexperienced medical student - concerned non classical presentations of myocardial infarction. Three of the five patients had not realized they were having a myocardial infarction (MI). Furthermore, the question regarding MI presentation had not been asked in the interviews of the first two patients, but had emerged in the third interview and was subsequently asked about in the following interviews. One of the male patients described dismissing his symptoms because they did not fit his expectation of an MI:

> It was in the shower. Felt like I couldn't put my head under water... I was going to wash my head, and I thought, 'I can't do this. I can't put my head under the water.' Real claustrophobic ... And then I felt ... shortness of breath, still hurting a little bit in the chest, but it passed. My wife wanted to call 911 but I said, 'It's gone now.'

Another male patient describes his symptoms as having most likely been present long before his MI:

> The first thing to say is I wasn't sure it was a heart attack at all. I didn't know I was having a heart attack. And, uh, when I look retrospectively back to what had happened, I realize that over about a week-long period, I had been having, uh, what I took to be very, very bad indigestive upper gas pain in my stomach...I had [it] in the past, it probably was angina and I didn't know it.

Because all HAT patients had "Q-wave" infarctions, which are not small heart attacks, what to do with this information is not clear. The chapter after next will

discuss what hopefully can be done with the such information. First, however, is a discussion on the limitations of this study.

CHAPTER FIVE: LIMITATIONS

This study bears several limitations which must be mentioned. First and foremost, this study is limited by the small number of interviews. Although 10 interviews were obtained, this corresponds to an *n* of five couples, which greatly reduces the power of the data. Furthermore, a strong selection bias factored in who chose to participate. As one male patient stated concerning his refusal to participate, he did not want to "discuss stress at this time." This may imply that those couples who chose to participate were either better suited at managing their stress, had lower levels of stress, or were more willing to discuss stress. This in turn makes the results non-generalizable to a larger population of AED recipients.

The subjectivity of participants' reports can be considered a limitation. There might be recall bias at play, where a participant might either down-play or highlight his or her experience based on what s/he feels the interviewer is seeking. Furthermore, the subjectivity of self-assessment must be considered. For example, one person's sensation of stress may be another's relaxed state. Lastly, many confounders may be present that would alter data given by participants. Examples of such confounders are denial of illness, presence of co-morbidities, use of anti-depressants, and perhaps an oversimplified understanding of CPR and defibrillation. To illustrate the presence of co-morbidities, one male patient said:

> [Having heart disease] really hasn't changed my life...What's changed my life, if anything has, has been having two false hips and the stenosis that's set in.

Another male patient suffered from painful diabetic neuropathy which took the forefront of his attention compared to his history of heart disease. Another female patient had debilitating back trouble and a colostomy resulting from an ischemic bowel, and these served to hinder her daily activities much more than the risk of another cardiac event.

The presence of denial presents an interesting situation. Long-term denial is associated with poorer prognosis among patients recovering from MI, because, it is argued, a patient who is in denial will be less likely to acknowledge the presence of cardiac symptoms and seek medical help. One early AED study echoed this concept when it found that the presence of denial might in fact be detrimental to appropriate AED use and placement in the home.[36] Denial is indeed present among at least one of the couples interviewed, as evidenced by an interaction between one male patient and the interviewer:

> Are you the patient with the heart trouble?
> Apparently.
> Apparently?
> I don't seem to have any problems, but, uh, I did have an event.

Therefore, denial might also be affecting a participant's responses to emotionally heavy questions.

A participant's oversimplified understanding or vision of what CPR or defibrillation entail could also affect interview responses. For instance, one male patient said:

> I don't feel that ... [defibrillation] is terribly invasive, because there are no needles. To me, needles are invasive. I would be under 10 times the stress if I had to give him a hypodermic or something like that.

This response to defibrillation suggests that a participant's feelings about defibrillation may not reflect the actual requirements of the procedure. Many studies in the literature have shown that public perception of CPR and defibrillation, especially as they are portrayed in the entertainment media, does not match real statistics of survival.[45, 46] Both lay public and medical professionals have been surveyed and have found to consistently over-estimate the success and ease of performing defibrillation and CPR.[44] This is not to suggest that all participants enjoy a false sense of confidence regarding defibrillation or performing CPR. Nevertheless, may affect interviewees responses.

Lastly, the subjectivity that the researcher brings to the process is a limitation. In bringing into the interview design her own expectations and hypotheses, the researcher may bias interview structure. The researcher was not blinded to AED status of participants. The researcher used personal judgment in deciding whether a couple was anxious or interacted at a lower baseline functionng. Furthermore, both interview technique and analysis of transcripts

are subject to the researcher's internal biases. It was the hope of the researcher that having several different transcript reviewers would help to diminish the latter.

CHAPTER SIX: DISCUSSION

Ingredients of Successful Home AED Placement

Based on the data collected in this study, one might wish to conclude that psychosocial aspects do not explain why AED use in the home has not been successful. As evidenced by the couple with difficulty, it is very likely that AEDs do have some stress associated with their placement at home. Furthermore, this study confirms the finding of previous home AED studies that some couples will have trouble adjusting to the idea of defibrillation. Yet because of the limited sample size and strong selection biases, the results cannot make a broad conclusion regarding the net effect of home placement of AEDs on a family's anxiety, depression, or distress.

However, what this study can comment on is what it takes to have a positive experience with home AED placement. To begin with, a couple needs good baseline functioning. As previously discussed, this suggests that the way in which a couple has dealt with previous life stressors is predictive of how they will deal with receiving an AED into their home. A high level of baseline functioning corresponds to a certain level of trust, intimacy, acceptance, and forgiveness between partners. It also implies successful communication, and requires cohesion and a sense of union between partners.

The second ingredient is the manner is which the couple relates to heart disease and all the lifestyle changes that come with it. For example, how does

the couple manage changes in diet and exercise? How do they relate to a new identity of having heart disease? Although this is impossible to separate from how a couple functions, I propose that a significant amount of how a couple relates to the presence of heart disease is determined by how the couple learns about the presence of heart disease, such as circumstances of the first cardiac event. The more emotionally traumatic the first event, the less control is perceived by the couple, and the harder the adjustment will be. Data in the literature supports the idea that survivors of SCA have a higher incidence of post-traumatic stress disorder, which is in line with increased emotional trauma surrounding the event.[113, 114]

The other ingredients proposed include individual psychology and levels of social support. Individual psychologic disposition and temperment will affect how an individual responds to the possibility of defibrillation. Socio-economic status, such as resources, education, and health care, has been mentioned in regards to home technologies as more important to quality of life than the severity of illness.[63, 64] The study sample could thus be viewed as biased in that participants all enjoyed a moderate-to-elevated socio-economic status, which could in turn be resulting in their general high functioning and high quality of life. Social support, both perceived and real, and both on a community and an individual level, is also very important to adjusting to having an AED at home, as well as managing heart disease in general. There are, of course, many other aspects to this recipe that did not emerge from data gathered in this study.

Yet it must be asked whether these necessary variables are also sufficient to ensure a positive experience with home AED placement. Even with all the variables in place, a person called on to defibrillate a loved one may have trouble actually going through with it, as was seen in early AED studies. Or, the partner might mistake agonal respirations for signs of ventilation and not initiate AED use. On the flip side of that, a participant who appears nervous about the possibility of defibrillation might in fact perform effectively during an event.

In addition, as previously mentioned, many people (medical professionals as well as lay persons) have a false conception of the chances of survival following CPR or defibrillation. This may be factoring into participants' sense of confidence regarding the possibility of having to defibrillate or perform CPR. It is likely that, in spite of all the necessary steps occurring at the necessary timing, a victim of home SCA would not survive. A family member who performs defibrillation at home might have strong feelings of guilt, disappointment, or anger at a negative outcome, especially when contrasted with high expectations of a positive outcome. This, combined with the obvious potential for emotional trauma at having to defibrillate a loved one, might cause a difference in feelings about home AED placement after deployment takes place. Therefore it is central to the exploration of home AED use that first-responding family members be debriefed or interviewed after AED deployment.

AED as a Psychosocial Variable

The effect of an AEDs on the psychology surrounding MI is of considerable importance. First, any type of intervention following an MI that affects a patient's mood, specifically level of anxiety and depression, will have repercussions over that patient's prognosis and risk for further cardiac events, including SCA. Second, an intervention that affects a family's perceived level of distress in the recovery period will affect that family's quality of life and psychosocial functioning.[83] In particular, a spouse who feels extra burden and responsibility placed by the possibility of having to perform defibrillation or CPR could affect family psychosocial functioning. This would have direct repercussions on healing. Third, any individual eligible to have an AED at home would be of higher socioeconomic status, with access to health care either through insurance or through self-pay, which is associated with improved cardiac outcomes.[89]

In their discussion of their findings, Hemingway and Marmot explain that social supports and networks are signified by the number of a person's social contacts and the quality of those interactions, of which emotional support and confiding support are important parts.[86] It is important to note that marital status, or living with a domestic partner such as home AED use requires, is a simple measure of social support. Therefore, in this circumstance, AEDs are a reflection of a psychosocial factor around an individual and a couple.

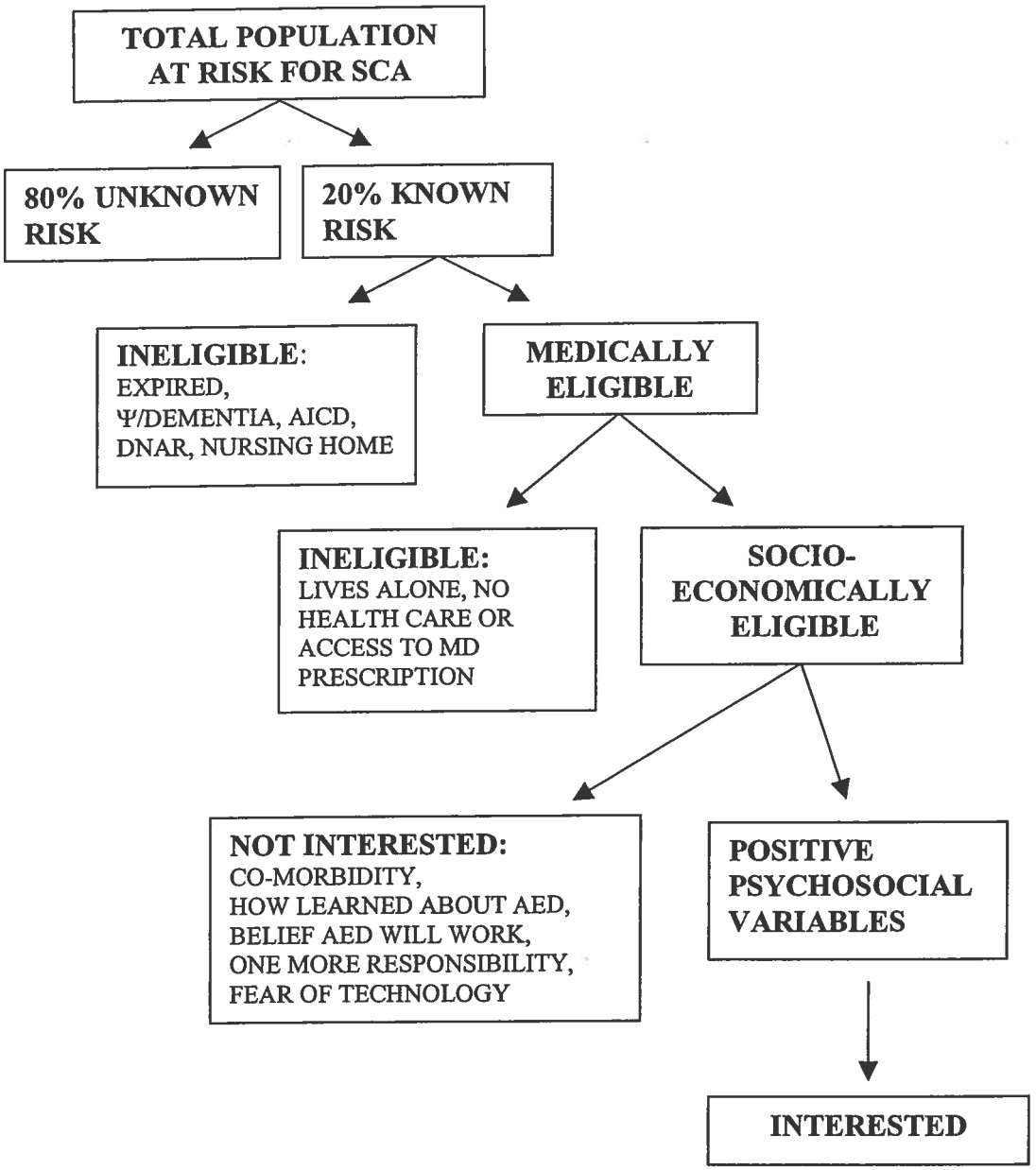
Yet AEDs, arguably, could be seen as not only a reflection of social support but a form of social support themselves. They may be a form of reassurance and support in themselves due to their potential to provide a sense of control over the threat of SCA. Furthermore, because long-term denial is associated with poorer outcomes, one could postulate that an intervention at home counteracts denial by forcing a patient (and family) to face his or her illness. Simply by being trained to use the device an individual obtains a certain level of education and awareness regarding both the intervention and the illness. The temporal relationship between denial and prognosis inversely mirrors the temporal relationship between apnea monitors and stress, and this can also be looked at as another way of explaining an AED as a tool for prognosis.

However, the relationship between AEDs and denial could work in the other direction, in that long-term denial can decrease AED use. Denial could be a barrier to AED use if a patient or family is less likely to consider a cardiac event as taking place. Additionally, denial could facilitate the "forgetting" of an AED, such as where they keep the AED, whether it is discussed with many friends and family members, or how a family conceives of having the AED at home. All of these variables might affect the outcomes for survival of at-home sudden cardiac arrest.[115] Thus, any force that might affect prognosis, could do so in either a positive or a negative direction. The interrelatedness of an AED to these many variables suggests that it in itself is a psychosocial variable with the power to affect prognosis. However, in which direction remains unclear.

Barriers to AEDs in the Home

Returning to the original question posed in the introduction, one can think of several general categories for the dismal survival outcomes found in early AED trials. It is possible that the lack of success could be due to lack of sufficient population-density in the home. Because SCA is a population-density occurrence, and it is possible that the survival of SCA may also depend on enough people being around to improve the odds that all necessary steps in the "chain of suvival" might take place. Second, something inside the home may be preventing effective deployment of AEDs. This could be due to psychosocial issues that arise from having an AED at home as was explored in this study. Mostly, however, these studies were plagued by problems with recruitment, which suggests a third category, that not enough people want AEDs in their homes, reducing the power of home AED studies to detect a difference in survival outcomes.

This last category could possibly be augmented by increasing the number of AEDs in private homes, and therefore it is useful to examine barriers exist that prevent a high-risk individual from receiving an AED at home. Using data provided by HAT screening information, the following chart can be drawn:



This chart highlights the different steps which progress towards home AED placement. To begin with, an individual must be at know risk for SCA. That in itself presents a problem: as many as 80% of individuals at risk for SCA may be unaware of their risk. Moreover, of those 20% that are aware of their risk, what is the cutoff point between low risk, and high risk? Individuals at

extremely high risk for SCA would most likely receive an implantable cardio-defibrillator (ICD). People determined to be at sufficient risk, must also be medically eligible, without terminal co-morbidities, psychiatric illness, or dementia. The individual must be socially and economically eligible: if an individual lives alone, an AED at home will have no use. Because AEDs are expensive and require a physician's prescription, access to health care is also required to obtain an AED. Based on numbers provided by HAT, approximately 300 Kaiser patients were screened for eligibility. Of those 300, 118 were sent introductory letters to join HAT. This corresponds to 39% within a population that by definition has access to health care.[37]

As a final point, an individual and his or her partner must be interested in having the AED at home, and here is where psychosocial aspects fits again into the picture. Of those 118 individuals sent introductory letters to join HAT, a randomized controlled study, only 19, or 16%, accepted the offer to enroll. This is lower than the data provided by Moore et al., although not a randomized controlled study, that 53% of all eligible AED recipients indicated willingness to receive one at home. So what is happening at this last step of AED eligibility? McDaniel et al. found that some individuals were not interested in having an AED at home due to an "unwillingness to accept responsibility" for defibrillation, as well as a fear of technology. Furthermore, both Moore and McDaniel found that the partner of the patient was more likely to refuse home AED placement than the patient. [11, 12] I would argue that psychosocial variables

are again at play, and represent another modality by which home AED use might not improve survival outcomes. Further research looking into why couples do not want an AED at home could provide valuable information.

The Utility of AEDs in the Home

In spite of the great success of AEDs seen in the public setting, the utility of AEDs in the private setting has not yet been confirmed. If AEDs at home are found not to be beneficial, negative psychosocial aspects can always be pointed to as one of the causes of their failure. Yet in contrast, if home placement of AEDs is found eventually to work, the psychosocial aspects of their use may diminish in comparison to the importance of increased survival of SCA. Negative psychosocial aspects attributed to the device at home may be dismissed a are side-effects of a medical therapy.

Discussion about the utility of AEDs in the home would be remiss if it did not include mention of the implantable cardio-defibrillator (ICD). Moss et al. recently demonstrated that ICDs prolong life among patients recovering from myocardial infarction.[68] In other words, ICDs pose a significant barrier to home AED use because they work. The patients in Moss' study all had ejection fractions of less than 30 percent, which raises the question of where to set the criteria for a patient to receive an AED at home over an ICD. There are, in addition, significant side effects to the malfunction of an ICD, not the least of which is severe anxiety among recipients of unnecessary shocks.[69-71] Thus, the

medical niche for AEDs at home is under evaluation. Whether an individual might be treated aggressively and receive an ICD may also depend on other factors as well, such as philosophy of the treating physician and age and physical condition of the patient. Nevertheless, if a physician is truly worried about the survival of a patient, he or she might prefer to implant an ICD in lieu of the potential gamble presented by use of an AED at home.

Furthermore, it is important to determine if certain populations are eliminated from the opportunity to have an AED at home. For example, 3 out of 10 older Americans live alone, which amounts to approximately 9 million people. 80 percent of those who live alone are women.[116] Therefore, this population disproportionately bears the burden of ineligibility. What kind of modifications must be in place to allow this growing population access to the same kind of interventions? Perhaps a sort of "neighborhood watch" approach may help older individuals living alone in the community.[117]

The last point to make in the discussion of the utility of AEDs is their cost-effectiveness. At this point, the cost-effectiveness of AEDs both in the home and outside of the home is still being debated. Some argue that mass production of AEDs could cause their cost to decrease, thereby increasing cost-effectiveness.[32] However, as the effectiveness of AEDs in the home has not yet been determined, the cost-effectiveness of their home placement is not yet of pressing nature. The cost-effectiveness of AEDs is a very important topic that has not been addressed in this paper.

Questions for Further Research

To conclude, what questions does this study bring up for further research, and how does this study speak to future, larger studies addressing home AED placement? To begin, it will be important to interview HAT participants after use of an AED to find out how effective the training videos are in preparing individuals for an event. Given the undeniable trauma of witnessing a loved one collapse, it will also be important to see how "family-first-responders" react to having to use the AED, and if those feelings are affected by either a positive or a negative outcome.

Another question yet to be answered is how to identify which couples might have a harder time adjusting to the presence of an AED in their home. This could perhaps be achieved by surveying a larger sample size from the knowledge gained in this qualitative study. Questions to be included in such a survey would include inquiries into the presence of co-morbidities and the disabilities associated with them, baseline functioning of a couple (already in use by the HAT study), where the couple might place the AED and how they would come to agreement on that subject, and whether the couple had discussed the how their AED fits in with their community of neighbors.

The questions regarding lack of interest in participation, both in receiving AEDs and discussing AEDs among those who have them, pose significant challenges. Protocol for HAT did not provide a method by which to collect data about couples who declined enrollment in HAT. It was difficult, given the

design and protocol of this study, to get a good sense of why couples were not interested in discussing their AEDs, because once they declined the invitation to interview the researcher was not allowed to contact them further for obvious ethical reasons. Unwillingness to discuss could be a function of many things, such as busy schedules, high levels of stress or poor managing of stress levels, significant co-morbidity, or the "sick of being sick" syndrome. However, because many of these possibilities include psychosocial variables, such information would be extremely useful to future studies about home AED use.

Another issue that arises from this study involves the increasing trend of technology-driven home interventions: namely, how does home AED placement speak to this phenomenon? Increase in caretaker burden – albeit slight in most cases – increase in reassurance, no significant increase in patient autonomy, and mixed positive and negative responses were seen among AED recipients. Literature review shows that the effects on quality of life from having an AED at home mirror the effects of other home-placed technologies, in spite of different mitigating circumstances surrounding each example. What are the qualities of the interventions that work best at home? Furthermore, is there a limit to what is appropriate to ask patients to do at home? At what point does the increasing use of home care reflect more a need to cut costs than a need to provide comfort and autonomy to patients and their families? These are important questions to families who are, in the current medical climate, required to be patients and consumers simultaneously.

In conclusion, the "big picture" of how to improve survival from sudden cardiac arrest must be assessed. Huge amounts of effort and resources have been poured into the grim problem of sudden cardiac arrest in this country, yet to date most of the research has been centered around how to survive SCA after it has occurred. Yet SCA continues to be a significant killer in this country, ridiculing our efforts as inefficient and ineffective. Therefore, given that heart disease will always be a national affliction, the most important research question to be asked in the future about SCA is how to accurately predict its occurrence. As Eisenberg and Cummins, two pioneers in the field of AED research, have written, "Automatic defibrillators for cardiac arrest are analogous to iron lungs for polio. When effective prevention of polio appeared, iron lungs vanished."[118] Until this question is answered, we will have to work within the limitations of what is available, and presently, automated external defibrillators can at least offer some a chance.

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APPENDIX A

PSYCHOSOCIAL FACTORS RELATED TO HOME AED USE: INTERVIEW DESIGN

Interview Format: Open-ended questions with prompts

Domain one: Living with CHD
"Tell me what its been like for you/ your spouse/ study partner since the heart attack.
"Has it been different from before the heart attack?
"To what do you attribute any changes?"

Prompts:
How long ago was your/ your study partner's heart attack?
How did you feel in the months right after your/ your study partner's heart attack?
Is that different from now?
Have you/ your study partner been able to return to work?
What kind of physical activity can you/ your study partner do since your heart attack?
How would you describe your/ your study partner's mood since the heart attack? (Anxiety, depression, sense of control,)
Right after your/ your study partner's heart attack?
Recently?
How do you feel about your/ your study partner's heart disease?
Has this changed at all recently?
How often would you/ your study partner see the doctor for checkups?
How is your/ your study partner's memory since your/ your study partner's heart attack?
Recently?
Ever have trouble concentrating right after your/ your study partner's heart attack?
Recently?

Domain two: Living with AED versus CPR
"Tell me about your/ your study partner's life since you got the Automated External Defibrillator (AED)/have been trained in cardiopulmonary resuscitation (CPR):
"To what extent does having the AED/knowing CPR affect your daily activities? (By "daily activities", I mean 'what you do or how you do it'.
"Is it different from before?
"Why do you think it's different/ not different?"

Prompts:
How concerned do you feel about the threat of another heart attack? Is this different from before?
Have you noticed any change in your mood?
Anxiety, stress, increase or decrease?
Sense of control?
Confidence?
Sense of security or reassurance?
If so, why do you think that is? Or, why not?
How nervous are you about the possibility of needing/using CPR/AED?
How do you feel about using the AED/ performing CPR?

Confident? Intimidated?

What is your sense of the responsibility placed on you by learning CPR/AED use?

(ie – is the AED one more thing to take care of? Does it give an increased sense of confidence in management of CHD?)

Have you noticed any change in the way you and your partner communicate since enrollment in HAT?

Domain three: Domestic relationship and living with AED versus CPR

"I'd like to learn about what you and your [spouse] have been like together since you got the AED.

"Has the AED/ learning CPR affected your relationships with your spouse? Family members? Friends?

"If it has affected your relationships, in what way?

"Why do you think it is/ What do you make of it?

"Is this any different from before you got the AED?

"From before you had the heart attack?

"Why do you think it's different or not different?"

Prompts:

In general, how do you get along?

How much time do you spend together?

Do you ever bicker?

Do you ever get very angry at each other?

How do you resolve your disagreements or arguments?

Do you feel care-taking is balanced between the two of you?

How do you express affection for each other?

Do you talk about or discuss your/his/her illness?

Do you ever feel your partner is protective or overprotective?

How do you support each other?

Do you ever feel like you burden your partner?

Do you talk a lot?

Do you ever feel your partner is controlling?

Domain four: Other feelings about home AED use/ home CPR

"*Did you have any reservations to joining the HAT study? Did you have any hopes when joining the study?*"

Prompts:

Did you have any expectations when you joined HAT?

Do you feel they have been met? Why or why not?

Have any issues come up over having the AED at home?