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## **Expanding the Limits of Evidence-based Medicine: A Discourse Analysis of Cardiac Rehabilitation Clinical Practice Guidelines**

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**Abstract: This paper identifies the promises and pitfalls of relying on guidelines derived from evidence-based medicine for post-heart attack education, and identifies how adult educators can expand current cardiac rehabilitation practice beyond its emphasis rational individual behavior change. Assumptions behind the "evidence" are discussed.**

### **Background**

More than 1.5 million middle-aged and older adults in the U.S. have a heart attack each year and half a million die - thus making heart attacks the leading cause of death. Trends are likely to continue as the population ages (American Heart Association, 1999). Thousands of studies over the last several decades have shown that maintaining a healthy lifestyle (diet, exercise, stress reduction and not smoking) can effectively manage symptoms, delay or prevent subsequent heart attacks, and lower mortality and morbidity rates (AHCPR, 1995). While seemingly simple, many people find these changes difficult and most do not succeed at maintaining them - even after a heart attack. Education helps somewhat. Six-week outpatient cardiac rehabilitation is the gold standard for post-MI education. About 38% of eligible patients are referred to and participate in cardiac rehabilitation and about half of participants maintain lifestyle changes. Cardiac rehabilitation, therefore, accounts for at most 20% of improved lifestyle behaviors. Quality varies from "bare-bones" monitored exercise to time-extended comprehensive programs with peer support groups, family and individual counseling, meditation classes and guest lectures. Participation rates, and long-term benefits generally vary according to class, race, educational level and geographic proximity to quality medical centers (Bittner, 1999). Barriers to referral and participation have been identified as gender (women participate less), age (older people get fewer referrals), no insurance inconvenient location and hours.

### *Evidence-based Medicine*

The U.S. Agency for Health Care Policy and Research (AHCPR, 1995) responded to such variance with the publication of evidence-based *Cardiac Rehabilitation: Clinical Practice Guidelines*. The *Guidelines*, developed by a primarily expert physician panel, used evidence from a comprehensive analysis of published *scientific research* evaluating the effectiveness of various cardiac rehabilitation programs. The panel concluded that cardiac rehabilitation programs should be extended beyond the typical six weeks, include comprehensive education and psychosocial support, better address individual needs, and expand beyond formal clinical settings to telephone case management and community and home nursing. These recommendations thus challenge the increasingly for-profit U.S. health system to expand beyond

purely biomechanical, exercise-only models. However, educators must consider how relying solely upon such evidence may unnecessarily narrow the scope of what people really want or need to learn after a heart attack. Certainly, I do not argue against promoting individual lifestyle changes, but a laser focus on lifestyle change outcomes may preclude opportunities for meaning making and clarifying goals or purpose; reflecting on social and economic conditions that increase heart disease risk; or increasing skills to maneuver the inequities in health care bureaucracies; or learning to change within one's social unit. Some believe that such a narrow focus compromises long-term success (Merz and Rozanski, 1996; Ornish, 1990). This paper, therefore, addresses the questions of why participation and "adherence" rates remain so low even in comprehensive programs, and how disparity along geographic, class, race and gender lines may be implicitly built into the cardiac rehabilitation structure. It does so by examining how the panel's assumptions about heart disease bump up against other paradigms of heart health, and social inequities. Finally, it proposes expanding cardiac rehabilitation's adult education theory repertoire beyond self-efficacy and self-directed learning.

### **Methods**

I used Schatzman's (1991) dimensional analysis, a variation of grounded theory method, to compare the evidence included in the *Guidelines* with evidence that was not included. Dimensions of analysis include participants' characteristics (gender, age and insurance status), the underlying assumptions of selection criteria for included evidence. Excluded evidence came from qualitative and quantitative studies about the social, emotional and economic aspects of heart disease. These studies were found by searching the public health, nursing, psychology and biomedical literature, as well popular books written by scientists whose wingspread now embraces broader metaphors of health and learning.

### **Evidence Included into the Court of Medical Policy**

The expert panel searched MedLine, CINAHL, and PschLit for published reports describing the *outcomes* of various cardiac rehabilitation interventions - exercise training, education, counseling, and behavioral interventions (AHCPR, 1995, p. 105). Outcomes included those measured by the health system (e.g., cholesterol, cardiac function) and those experienced by the patient (e.g., return to work, or reduction in morbidity or mortality). Of the 900+ articles found in the search, 334 were selected for critical review. The recommendations were based on the strength of evidence of how specific interventions (e.g., smoking cessation) affected specific outcomes (e.g., mortality). Evidence was ranked according to the rigor of the study designs (AHCPR, 1995, p. 24-25). The highest ranked were randomized studies with statistically significant results ( $p=.05$ ); the lowest were observational studies.

#### *Critique of the Evidence*

*Randomization, generalization and p05.* The randomized control study is regarded as the king of study designs for evaluating intervention effects. Its purpose is to reduce variance within and across groups of a *representative* sample in order to generalize to a larger sample. Of course, doing so assumes that subjects share similar learning needs, goals and capacities. In this case, "evidence" was constructed from studies whose subjects were overwhelmingly white educated

men with insurance coverage. The panel acknowledged that inconvenient location and lack of insurance or physician referrals biased the sample and called for more inclusive studies. However, it did not suggest that current emphasis on behavior change outcomes might have also discouraged participation by women and minorities. Furthermore, accepting only studies with statistically significant sample-wide effects into the evidence by definitions excluded studies with lower overall significant effects that helped a minority of the sample a great deal.

*Evaluating systems instead of learners' experience: the educational experience as a black box.* Typically, randomized evaluation studies of cardiac rehabilitation outcomes do not describe the program or the learners' experience. Instead, they provide a few phrases about the program, such as "nutritional counseling was provided" and evaluate programs based on a set of sample-wide outcome or criterion variables. Therefore, educators and researchers set the learning goals with the assumption that they match the learners' goals. But how close is the match?

*Theories and assumptions.* While published studies do not describe the teacher-learner interaction, we do know that three interlocking health behavior change theories inform cardiac rehabilitation programs (Medich, Stewart and Chase, 1997). These include: a) the health belief model - not changing poses an unacceptable health threat; b) self-efficacy - belief that one can accomplish the change and the change is worthwhile; and c) stages of change - change is a linear process that requires contemplative activity prior to action (Rhodes, Fishbein and Reis, 1997). Thus, exercise or diet programs help individuals by coaching, cueing, skill building, and modeling similar others. The assumptions behind these theories include the following. First, interpreting a heart attack and implementing a change process can be made into a purely rational endeavor. Second, a heart attack is sufficient motivation to change. Third, individuals *sustain* a belief that changing their lifestyle will improve their health and extend their life. Fourth, people place a high priority on their health and will put forth effort to improve it, even at the expense of other people's expectations. Fifth, people have sufficient life skills, and personal and social resources to attempt and succeed with a new lifestyle. Sixth, people are self-directed learners. And finally, people experience living beyond a heart attack as an individual endeavor. However, since the majority of graduates do not maintain exercise, diet or smoking cessation at six-month follow-up (Burke, Dunbar-Jacob and Hill, 1997), perhaps programs based on these learning assumptions do not meet participants' needs (let alone the needs eligible non-participants).

### **Learning from Inadmissible Evidence: Implications for Adult Educators**

The panel was specifically charged by the National Institutes of Health to develop cardiac rehabilitation recommendations through a systematic review of evidence from existing programs. However, as educators we are free to consider evidence and experience that fall outside the *Guidelines'* criteria. Studies fell into two categories-making meaning of the event by reflecting on emotions, relationships and spirituality, and programs that integrated broader paradigms.

#### *Descartes Meets Integration: Emotions, Relationships, and Spirituality*

*The heart connection.* Social support has been linked significantly to increased heart attack survival, while a lack of social support has been linked to increased mortality (Anderson, Deshais and Jobin, 1996). Ornish (1998) hypothesizes that positive social support may be the

most important factor in reducing incidence of and decreasing mortality from heart disease - more important than diet, exercise, and so forth. In fact, a 50-year study of a close-knit Italian American community in Roseto, Pennsylvania, found that incidence of cardiovascular was low despite high levels of obesity and other lifestyle risk factors (Wolf, 1992). Marriage with a high degree of intimacy and instrumental support has been linked to overcoming post-MI depression, earlier hospital release, and improved lifestyle modification (Bovbjerg, et al., 1995; Frasure-Smith, et al., 2000). Lack of social participation or comfort from religious strength tripled the risk of death within six months (Oxman, Freeman and Mannheimer, 1995). Social support can also have negative consequences when families are intrusive, overprotective and demanding, or sabotage efforts to change behavior through lack of support or confidence (Burg and Seeman, 1994). Thus, it stands that already-stressed relationships may be less resilient to the challenges of illness and associated financial stresses. In sum, there is abundant evidence that social relationships play a significant role in recovering from a heart attack. *Cardiac rehabilitation programs should offer family education, but few do!*

*Heart and soul: the spiritual connection.* Recently, several researchers have written about the role of faith and belief in stimulating our innate ability to heal (Benson; 1996, chapter 8). Spirituality is broadly defined as making meaning of a life-threatening event, facing one's mortality, and coming to new understandings and meaning about one's purpose and values in life (Camp, 1996). For instance, Camp found spiritual issues became heightened with the crisis of facing bypass surgery. Spiritual integrity consisted of *having faith* that one could transcend the current materialistic situation; that the hospital staff was capable; and that God would "get them through" the surgery. New perspectives resulting from spiritual experience may influence long-term behavior changes that reduce heart disease risks. Crisis can either develop or threaten one's faith; therefore cardiovascular nurses should integrate people's spiritual beliefs into care.

Unfortunately, the infrastructure that delivers bio and behavioral medicine has been slow to integrate these findings into practice. Most cardiac rehabilitation programs use rational ways to adopt and adhere to lifestyle behaviors, but neglect the full *emotional* impact of the illness (Merz and Rozanski, 1996). However, patients have been reportedly slow to take advantage of available integrative services (Cathy Bonus, personal communication). These phenomena are artifacts of the long ingrained Western mindset that has philosophically followed the Cartesian separation of the mind and body (Damasio, 1994). In this metaphor, health is defined as the absence of symptoms rather than positive well-being - or human flourishing (Ryff and Singer, 1998), mind and spirit are treated separately from biological systems. Medical treatment is analogous to repair shops with the goal of restoring to neutral rather than to optimal health or human flourishing (Ornish, 1990; Ryff and Singer, 1998).

*Metaphors of the heart: pumps and valves, and the seat of emotion and soul.* Dean Ornish (1990) reframed the metaphor for the heart from an oxygen exchange unit (pumps, valves and tubes) to a spiritual and emotional exchange unit. The mechanistic metaphor fixes the broken heart with surgical procedures, powerful medicines and cognitively driven, action-oriented risk-reduction behaviors. The spiritual exchange metaphor *heals* the heart through self-reflection and self-forgiveness and feeding the heart and soul with what it needs. Ornish addressed this paradigm shift with a new program that included support groups, therapy, meditation and usual cardiac rehabilitation but with an extra low-fat diet. Randomized studies showed the Ornish group had

reversal of heart disease with no medication while the usual care control group with medication worsened (Gould, et al., 1995). However, Ornish's maverick-like critique of the bio-behavioral model has wrought criticism that people are unlikely to follow such a program (Connor and Connor, 1997). Nonetheless, Franklin et al. (1995) found that people in a rural southern community maintained the program with on-going program support, a low-fat regional cookbook, and monthly participant potluck dinners. Medich and colleagues (1997) found that an integrated mind-body program with daily meditation and cognitive therapy led people to a transformative state across biological, psychological, social, spiritual and behavioral experiences. The authors concluded that (p. 69), "*Transformation represents an expression of consciousness with new ways of seeing, being, and responding. [It] also reflects personal balance or a greater sense of control, order and harmony within one's life as perceptions of vulnerability decrease.*"

*In sum.* New mind-heart-body-spirit metaphors that integrate how people make meaning of a heart attack reflect Mezirow's (1991) notion of perspective transformation after a disorienting dilemma, models of affective and spiritual learning (Tisdell, 1999), integration of the logical and intuitive (LaBouvie-Vief, 1994). They underscore the fact that behavior change is conditional upon prior and continuous meaning making (Wise, 2001). Some high-end medical centers have integrated these new metaphors, but most have not. While the mind-body metaphor challenges traditional medical and behavior modification models, it does not challenge social economic power structures or the traditional Western focus on individuality rather than on community.

### *Social Justice Education*

Several studies have reported that gender, class and race are barriers to cardiac rehabilitation participation (Bittner, 1999). Few, however, have reported on educational projects that work toward fundamental social change. Thus, popular education programs with a critical focus could help communities organize or lobby for universal health coverage, culturally competent health education programming, advocate for land use plans that encourage walking or biking instead of (such as community vegetable gardens, bike paths or mixed zoning), or help women advocate their health needs within strong patriarchal families. It is unlikely that such a curriculum would be allowed in formal cardiac rehabilitation programs. However, critical and feminist perspectives have been used in community and popular education movements to examine healthcare access, race and class issues, to examine the relationships between illiteracy, poverty and health, and to empower people to change their social relationships and behaviors (Corcega, 1992; Comings, Smith and Shrestha, 1994). In fact, one such program was found to improve heart health in a low-income rural community in the U.S. (Franklin, et al., 1995).

### **Summary**

In sum, the evidence-based *Cardiac Rehabilitation Guidelines* have challenged healthcare organizations to cover cardiac rehabilitation beyond the typical six-weeks, and to provide individual and family counseling and more educational opportunities. However, educators must also look beyond the rational behavior change educational orientation to include mind-body integration, transformative learning, and critical popular education to address issues of social justice and cardiotoxic social policy. Finally, as the population ages, more people will be facing heart disease and the need for education and skills to influence social policy.

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