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Cardiac Rehabilitation and Women: A Multi-level Information Access Approach

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Abstract:

According to the American Heart Association, "diseases of the heart are the No. 1 killer in the United States . . . Also, research shows that the onset of heart disease in women often differs from that of men. A recent study revealed that delays in receiving emergency room attention are significantly greater for women who show symptoms of heart problems than for men.

Education and information regarding exercise and diet modifications are shown to be helpful in promoting and maintaining a heart healthy lifestyle that may prolong life, particularly for survivors of cardiovascular events. As heart disease is the number one cause of death in women, an examination of the types information available related to cardiovascular rehabilitation and future health practices, as well as their points of access, is called for.

Patient information programs and/or follow-up referral services are not uncommon components of cardiac care units at many hospitals. The ways women, who have experienced medical treatment for a cardiac event, are provided appropriate health information is the focus of this paper. While there are several modes of communicating health information, it is the levels of consistency, breath, and depth that will be explored here. How do women learn of health information services after a cardiac episode? What is the role of the library (medical, public, academic) in providing information to this population? What is the level of collaboration between among medical and library/information entities?

This paper background research for a study of cardiac rehabilitation programs and female survivors that will address the following questions: What type of follow-up service is provided? What are the rates of adherence or adoption among women? Is the provision or acceptance of

relevant patient/consumer health information influenced by factors such as age, education, income, cultural differences, language, etc.?

Introduction

According to the American Heart Association, "diseases of the heart are the No. 1 killer in the United States . . ." The U.S. is not alone in this distinction. Other countries indicate that coronary heart disease (CHD) is at or near the top of their morbidity and mortality lists. In 2006, the Office of National Statistics in the United Kingdom stated that, "heart disease (including heart attacks) was the leading cause of death for both sexes in England and Wales in 2005 accounting for one in five male deaths and around one in six female."

By contrast**,** Asian countries such as Japan and China, historically, have reportedly been among the countries with the lowest rates of CHD. However, recent changes in lifestyle may be contributing to increased risks for cardiovascular disease in those countries. Those risks factors have been attributed to ". . . a higher fat diet, an increasingly westernised lifestyle, and a rapid decline in the level of physical activity" (Parry, 2004). In its *Atlas of Heart Disease and Stroke*, the World Health Organization (*WHO*, 2004) places the prevalence of heart disease in a deadly light:

> Heart disease and stroke kill some 17 million people a year, which is almost one-third of all deaths globally. By 2020, heart disease and stroke will become the leading cause of both death and disability worldwide, with the number of fatalities projected to increase to over 20 million a year and by 2030 to over 24 million a year (Mackay & Mensah, 2004).

The above concerns denote the global, near epidemic proportions of heart disease. A group of illnesses that previously was thought to afflict primarily people who were elderly or frail, are now being seen at higher rates, in younger populations and in parts of the world where CHD had not been nearly as widespread. In fact, "it is expected that 82% of the future increase in coronary heart disease mortality will occur in developing countries" (Mackay & Mensah, 2004, p. 48).

The complexity of the cardiovascular system and its relationship to and interaction with the human body, allows several conditions to be listed under the heading of heart or cardiovascular disease. A very broad definition in Dorland's Illustrated Medical Dictionary defines heart disease as "*any* organic, mechanical, or functional abnormality of the heart, its structures, or the coronary arteries" (*Dorland's Illustrated Medical Dictionary*, 1994, p. 483). Many or most of those conditions are beyond the purview of this paper.

For the purposes of this work, heart disease refers to those illnesses that are shown to be helped by cardiac rehabilitation. The Mayo Clinic (2007) list includes the following conditions:

Heart attack

Coronary artery disease

Heart failure

Peripheral arterial disease

Chest pain (angina)

Cardiomyopathy

Certain congenital heart diseases

Coronary artery bypass surgery

Angioplasty and stents

Heart transplants

Heart valve replacements

This paper is a brief exploration of cardiovascular disease and cardiac rehabilitation referral issues with a focus on women survivors of cardiac disorders.

Women and Heart Disease

Often, depending on the sex, cardiovascular disease manifests differently. In many instances, cardiology research has shown that the onset of heart attack, for example, is often different in women than in men. Until recently, physicians looked for certain "classic" symptoms in both men and women who thought they were experiencing heart problems. Those symptoms include crushing chest pain, numbness or pain along the left arm, shortness of breath, and sweating (American Heart Association, 2007). These symptoms were observed most often in men and cardiac events such as heart attack was thought to be a disease far more prevalent in males than in females. While some women with heart disease may experience the same classic symptoms as men, many women also present with other unusual signs and symptoms or have no symptoms at all. This matter becomes more troublesome when we learn that women, who may display observable signs of heart trouble, are not attended to in a timely fashion. A recent study revealed that delays in receiving emergency room attention are significantly greater for women who show symptoms of heart problems than for men (Concannon, et al. 2009). Moreover, for years, once attended to, women were misdiagnosed more frequently than their male counterparts. Based on the medical research at the time, miscalculations regarding, for example, dosage levels of prescription drugs, were found to be inadequate for the female heart patient. The source of information mainly revolved around clinical trials which typically had few if any females among

the study samples. Schiebinger (2003) wrote that “a consequence of extrapolating the results of male-only clinical data to female consumers is that women were (and still are) typically prescribed dosages devised for men’s average weights and metabolisms” (p. 974).

Nonetheless, these seemingly ominous circumstances are being studied by the cardiology research community. Cardiology researchers investigate the various influencing factors, such as gender, pre-existing conditions, heredity, environment, and lifestyle, in different populations. Just as important, these issues have caught the attention of heart health policy advocates around the world as well who campaign for more consideration in treating women with heart disease. On a more positive note, researchers have concluded that heart related ailments like those noted above can be treated successfully with lifestyle modifications and that existing heart disease can be improved, with certain therapies, such as cardiac rehabilitation (CR), preventing further damage to the heart and averting future cardiovascular events.

Cardiac Rehabilitation

Cardiac rehabilitation (CR) is designed to help survivors of cardiovascular episodes improve the quality of their lives by improving the health of their hearts. The U.S. Public Health Service and the Cardiac Rehabilitation/Secondary Prevention Performance Measures Writing Committee (Thomas, et al., 2007) offer this definition of CR:

> Cardiac rehabilitation services are comprehensive, long-term programs involving medical evaluation, prescribed exercise, cardiac risk factor modification, education, and counselling. These programs are designed to limit physiologic and psychological effects of cardiac illness, reduce the risk for sudden death or re-infarction, control cardiac symptoms, stabilize or reverse the atherosclerotic process, and enhance the psychosocial and vocational status of selected patients. (Thomas, et al., 2007, p. 264**).**

Cardiac rehabilitation include of the following components:

- Medical evaluation, consisting of assessment of health status, physical limitations, and cardiovascular disease risk factors.
- Physical activity, consisting of walking, cycling, rowing, jogging or some other endurance based exercise.
- Lifestyle education, consisting of information and guidance on diet and nutrition aimed at weight reduction as well as on smoking cessation and pain management.
- Support, consisting of help with adjusting to and navigating current or new health issues to avoid the possibility of depression and anxiousness.

CR programs are offered in various settings however, most take place in facilities that are affiliated with a hospital or cardiac care center. Most often, these programs are licensed and certified by the appropriate accrediting organizations; for example, the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) is one such agency in the United States. CR programs last between 12-18 weeks, with members meeting approximately three times per week. Primary aspects of CR, exercise and diet modifications are proven to promote and maintain a heart healthy lifestyle that can extend life, particularly for survivors of cardiovascular events. Grace, et al. (2002) states that, "In particular, it is now well established that cardiovascular mortality can be reduced by approximately 25% when patients participate in a multifactorial CR program" (p. 127). Nonetheless, there is a significant and long-standing problem with cardiac rehabilitation – it is largely underutilized in general and especially so in the case of women (Sanderson, 2005). In part, the amount of CR underutilization may account for equally high numbers of emergency room visits and rehospitalizations among some segments of the population, women being among them (Jencks, 2009).

Increasingly, patients are urged to take ownership of their own health and wellbeing, including deciding whether to take part in CR activities. However, beyond the notion of whether patients understand or value CR, cardiology researchers point to a number of explanations for low participation in such programs. Depression, anxiety or other psychosocial conditions, comorbid illness, and age as well as transportation and conflicts of time, are among the reasons cited in the literature as possible barriers to CR involvement and adherence (Grace, 2002; Halm, 1999). In addition, patients' perceptions and understanding about the content and procedures involved in CR may also play a role in their non-participation (Cooper, 2005). Clearly, all of these are valid concerns that should be carefully considered when patients are advised to join a CR program.

The abovementioned text serves as backdrop to the primary focus of this paper, which is related to cardiac rehabilitation referral practices and particularly as they may impact the heart health of women. CR is initiated at the point of care or upon discharge from a healthcare unit. Despite the disincentives mentioned above, it remains perplexing to know that CR referral is carried out at such low rates and that, by and large, women are referred to CR by their physician or other healthcare provider less often than are men. Even with what is known about the barriers to CR, the glaring question remains; *why* is cardiac rehabilitation undersubscribed to by both sexes, with women attending CR far less than men? And, can CR referral and hopefully participation, be increased? If so, what methods may be used to improve consistently low levels of attendance and compliance?

While the author proposes that CR referral rates can be increased, it may be prudent to consider that the exact opposite may be true. That is, even though CR programs have existed in many countries for more than approximately fifty years and participation has grown steadily, the proportion of cardiac patients who were not referred and hence, who did not receive the benefits

of CR, clearly outnumber those who have been referred (Bethell, 2000). Perhaps, cardiac rehabilitation referral has reached it plateau.

Cardiac Rehabilitation Referral – The Missing Links

Patient information programs as well as follow-up referral services are not uncommon components of cardiac care units at most hospitals. In the U. S., as in other countries, advising and accrediting bodies, like the American College of Cardiology (ACC), American Heart Association (AHA), and the American Association of Cardiovascular and Pulmonary Rehabilitation Association (AACVPR) issue clear procedures for administering cardiac rehabilitation to members, including proposed equipment, monitoring practices, and appropriate personnel. For example, in order to attain and retain certification, the *Guidelines for Cardiac Rehabilitation and Secondary Prevention Programs* are to be closely followed. As may be expected, much of the content in the *Guidelines* focuses on various courses of action for delivering CR. And while it does contain sections on referral to CR, the main emphasis of these and other guidelines is on the post-referred patient and activities within the program. That is, these texts are written with the assumption that most patients *are* referred and with little attention paid to methods of providing CR referral.

As stated earlier, low referral rates and membership in CR programs have been consistent problems for cardiac rehabilitation and secondary prevention plans. Noted barriers to participation continue to be investigated by researchers of various disciplines. One main reason offered often by recovering cardiac patients for not participating in CR is that they lacked information on CR, what to do next, and available assistance (Cooper et al., 2003; Tod et al., 2002). Thus, what appears to be 'a missing link' in the cardiac rehabilitation enterprise, in the U. S. and abroad, is a comprehensive information delivery system that is designed to help healthcare providers disseminate CR referrals to all eligible discharge patients. Such a system would also contain prompts, reminding healthcare providers to follow up on patients' CR status. At core, what is needed is the provision of timely and coordinated information about CR and next steps to improving heart health and limiting further cardiovascular damage.

The future of Cardiac Rehabilitation Referral

To guard against patients in need of CR from further falling through the cracks, a multilevel CR referral system that supports the coordination of referral and monitoring information among all relevant healthcare providers should be developed. Such an integrated system would need to enlist the capabilities of information technology in this area. This proposed system would also retrieve and record standardized, documented CR procedures and would serve as a resource for

all attending medical staff. This kind of arrangement would inform care providers at inpatient, discharge and outpatient stages, making them aware of the available CR and secondary prevention facilities and would assist them in providing patients with the appropriate aftercare information.

While there are several ways of communicating health information, it is the levels of consistency, breath, depth, and dissemination of information related to cardiac rehabilitation referral that are the underlying premises of this paper and on which future research will be based.

This paper serves as background for an upcoming study of cardiac rehabilitation programs and female survivors that will address the following questions:

- How do women learn of CR services following a cardiac episode?
- What are the protocols for providing CR referral information?
- Are those protocols influenced by age, education, income, language or cultural differences?
- How is CR referral achieved at the point of care?
- How is information technology utilized?
- What are the methods of information sharing regarding CR referral among medical staff?
- What types of CR referral information are provided (print, digital, etc.)?
- Are there supporting roles, pertaining to CR information and promotion, to be played by non-medical organizations such as social service agencies, community centers and libraries?

A large proportion of persons who experience a heart attack or other diagnosis of a heart illness should be referred to appropriate follow-up care. However, the history of low membership and adherence among women call for a concentrated effort to better inform both healthcare personnel and their respective patients about the advantages of recommending CR and the subsequent risks associated with non-participation. The next phase of this research is intended to respond to that call.

Conclusions

It is a well known fact that heart disease, though decreasing in some corners of the globe, is still the primary cause of death of women in many parts of the world. In the United States, as in other countries, cardiac rehabilitation programs have been seen as a way of improving the lives of

those living with coronary heart disease. The underutilization of CR programs in general and by women in particular present a long held quandary for many researchers interested in heart health. Certainly, referral to these programs at the point of care and upon hospital discharge is a first step for some heart patients. However, as the research reveals, many more are not referred or informed of the benefits of CR.

There is no lack of information about CR. Libraries, bookstores, and the Internet contain countless sources aim at the patient and consumer which recovering heart patients may find very helpful. However they cannot replace the actual recommendations for follow up care made by the healthcare provider. Thus, in addition to current CR referral practices and available consumer health information, it is simply imperative that a new paradigm be created to address the discrepancy between the availability of CR programs and the lack of participation by women.

An examination of the types of information available related to cardiac rehabilitation and the means by which that information is provided as well as the points of access to such sources is needed. In addition, a broad, aggressive information and communications approach is suggested to raise the profile of CR. Also, it is advised that strategies be developed to promote the importance of CR referral to a wider audience within the healthcare community and outside of it. Finally, the cooperation of all stakeholders on this issue should be sought vigorously. Consequently, the next phase of this work includes an investigation of the extant information and communication gaps at the point of care that may serve as barriers to CR referral services. It is anticipated that the results of this research undertaking will reveal methods for enhancing those services for all who need them and particularly for women.

REFERENCES

American Heart Association (2007). What is Cardiac Rehabilitation? Retrieved May 10, 2009 from http://www.americanheart.org/downloadable/heart/119620120447745%20WhatIsCardiacRehab%209_07.pdf.

Bethell, H. J. (2000). Cardiac rehabilitation: From Hellerstein to the millennium. *International Journal of Clinical Practice*, Marcj 54(2), 92-7.

Concannon, T. W., Griffith, J. L., Kent, D. M, Normand, S., Newhouse, J. P., Atkins, J., et al. (2009). Elapsed Time in Emergency Medical Services for Patients With Cardiac Complaints: Are Some Patients at Greater Risk for Delay? *Circulation: Cardiovascular Quality and Outcomes*, January 13. Retrieved March 21, 2009.

Cooper, A., Jackson, G., Weinman, J., & Horne, R. (2005, February). A qualitative study investigating patients' beliefs about cardiac rehabilitation. *Clinical Rehabilitation*, *19*(1), 87-96. Retrieved May 12, 2009.

Dorland's Illustrated Medical Dictionary, 28th Ed., (1994), Philadelphia, PA. W.B. Saunders Co.

Grace, S. L., Abbey, S. E., Shnek, Z. M., Irvine, J., Franche, R., & Stewart, D. E. (2002). Cardiac rehabilitation II: Referral and participation. *General Hospital Psychiatry*, 24, 127-134.

Jencks, S. F, Williams, M. V., & Coleman, E. A. (2009). Rehospitalizations Among Patients in the Medicare Fee-for-Service Program. *New England Journal of Medicine*, 360 (14), 1418- 1428.

Mackay, J. & Mensah, G**.** (2004**).** *Atlas of Heart Disease and Stroke.* Geneva, Switzerland. World Health Organization. Retrieved May 13, 2008 from http://www.who.int/cardiovascular_diseases/resources/atlas/en/.

Mayo Clinic Staff (2007). Cardio Rehabilitation: Building a better life after heart disease. Retrieved May 1, 2009 from http://www.mayoclinic.com/print/cardiac-rehabilitaton/HB00017/METHOD=print

Statistics News Release (2006). Coverage: United Kingdom. Theme Health and Care. Retrieved May 10, 2009 from http://www.statistics.gov.uk/pdfdir/hsg0506.pdf.

Parry, J. (2004). China and Japan face epidemic of heart disease. *BMJ*, September 18, 329(7467) (Retrieved May 13, 2009).

Sanderson, B. K. (2005). The Ongoing Dilemma of Utilization of Cardiac Rehabilitation Services. *Journal of Cardiopulmonary Rehabilitation*, November/December 25(6), 350-353.

Schiebinger, L. (2003). Women's Health and Clinical Trials. *Journal of Clinical Investigation*. October, 112(7), 973-977.

Taylor, D., Barber, K., McIntosh, B., & Khan, M. (1998, November). The impact of post acute myocardial infarction (AMI) depression on patient compliance and risk factor modification. *Psychology, Health & Medicine*, *3*(4), 439. Retrieved May 20, 2009.

Thomas, R. J., King, M., Lui, K., Oldridge, N., Pina, I. L., & Spertus, J. (2007). AACVPR/ACC/AHA 2007 Performance Measures on Cardiac Rehabilitation for Referral to and Delivery of Cardiac Rehabilitation/Secondary Preventions Services. *Journal of Cardiopulmonary Rehabilitation and Prevention*, 27, 260-290.

Tod, A. M., Lacey, E. A, & McNeill, F. (2002). I'm Still Waiting . . .: Barriers to accessing cardiac rehabilitation services. *Journal of Advanced Nursing*, 40(4), 421-431.