

# **Population Monitoring of Quality of Life for Congestive Heart Failure**

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## **Abstract**

The healthcare system has traditionally focused on treating disease at point of failure, such as life-saving surgery or intensive medical therapy. As demographics shifts more to an aging population, management of health-related quality of life and life-restricting disease becomes more necessary. Prominent among such diseases is congestive heart failure (CHF), which must be addressed as a major chronic health condition with its consequent effect on quality of life.

This paper examines the methods for monitoring the quality of life for congestive heart failure. Particular attention is paid to CHF-related questionnaires to derive lifestyle information directly from patients. Comparison is made with general quality of life instruments. Most commonly, these questionnaires are applied to small populations in limited situations.

New technology, such as the Internet, greatly expands the breadth and depth of health monitors by tracking status directly in patients' homes. This promises new levels of population management for heart disease.

“The concept of total well-being—psychosocial as well as physical—is often termed quality of life.... Central to the concept of quality of life and its measurement is that the assessment should include not only the actual event or function per se but also the patient’s perceptions of its impact on his or her life.” (1)

Population management of heart disease is a pressing national need, since it is the leading cause of mortality in the United States. Recent data state that in 1997 more than 31.4% of deaths were directly related to a cardiac cause. (2) Cancer, the next leading cause, was responsible for 23.3% of deaths. Heart disease and its late manifestation, heart failure, account for a large percentage of the healthcare budget while causing great suffering for patients and families.

The nature of heart disease is changing. As the Baby Boomer generation ages and the elderly population increases, congestive heart failure (CHF) is becoming more prominent. More than 75% of patients with CHF are older than age 65. (3) Coronary artery disease, largely due to surgery and medical regimens, is becoming less a cause of mortality than the leading subsequent cause of CHF. (4) (5) (6) (7)

The healthcare system has traditionally focused on treating disease at the point of failure, such as life-saving surgery or intensive and acute medical care. As demographics shifts result in an aging population, the management of health-related quality of life and life-restricting disease becomes of primary importance. Future concerns about CHF must thus address the management of a chronic health condition and its effect on quality of life.

This paper examines the methods for monitoring the quality of life for congestive heart failure. Particular attention is paid to lifestyle factors for CHF and CHF related questionnaires to derive information directly from patients. Comparison is made with more general health status and quality of life instruments. Most often, these questionnaires have been used for small populations and limited, specific indications.

New technology, such as the Internet, expands greatly the range and the depth of health monitors by tracking health status directly in patients’ homes. This ultimately promises new functionality for the population management of heart disease.

## **Quality of Life Factors for Congestive Heart Failure**

Congestive heart failure has many etiological factors. Much has been written about its prevention, its modification by lifestyles, its course with treatment, and its effect on patients themselves. The most common etiological factors are tobacco smoking, exercise, diet and nutrition. (8) (9) (10) (11) But there are many other related factors or associated conditions such as depression, obesity, the environment, and access to health care. (12) (13) In addition, subjective symptoms associated with a depressed mood and the emotional support given to patients with heart failure while in the hospital have been found to have prognostic significance. (14) (15)

Each of these factors has a close relation with congestive heart failure, at times as a causative and associative factor, at other times as a preventative or modifying factor. In all cases, the factors influence the occurrence and severity of heart failure while they themselves may be influenced by the effect that heart failure has on an individual.

Exercise in particular is thought to be a major determinant of health in congestive heart failure. Exercise training may be used to grade patients; in other situations exercise training is used to improve performance and endurance. But each individual is slightly different and programs need to be tailored on a personal basis, requiring an interactive exchange and a prolonged period of monitoring. (16) (17) (18) (19)

Associated illnesses, such as hypertension, chronic obstructive lung disease, stroke, diabetes, and peripheral vascular disease are vitally important either related to the etiology of congestive heart failure or as exacerbating illnesses that influence the course of disease. (8) Congestive heart failure itself, with time and disease progression, may be associated with any number of subsequent morbidities such as respiratory failure, gastrointestinal symptoms or renal disease.

But, as congestive heart failure becomes more prevalent, other symptoms such as fatigue, somnolence, gastrointestinal dysfunction or depression may be presenting symptoms. Wei suggests that atypical presentations of congestive heart failure have become the norm in the elderly. (20) This difference in presentation from the more conventional syndrome of fluid overload, dyspnea and fatigue reflects a changing population and altered physiological response. (21)

As times change, new information allows more precise determinations of particular disease processes. The work in Olmstead County, Minnesota demonstrated that many of the elderly developing CHF do not have a significant decrease in their left ventricular ejection fraction. Many such patients, in fact, have normal systolic function. Others remain in the border area between severe systolic dysfunction and a normal measurement. CHF in the presence of normal systolic function relates to a physiologic inability to accommodate to stress; such a condition may require a modified approach to therapy compared to patients who have CHF secondary to severe systolic function, perhaps retaining fluid, or whose ejection fraction is significantly below normal. (21)

Social and cultural factors also play a substantial role in congestive heart failure, they may override the physical and genetic factors in many cases. For example, a detailed study of 12,000 Japanese showed a striking relation between cultural support and heart disease. (22)

Japanese culture is collective, with the entire society acting as a supportive family to the individual; this dramatically decreases the environmental stress, which is a major health factor in heart disease. The study compared mortality due to heart failure in equivalent Japanese populations who lived in Japan, in Hawaii, and in California. Japan had the lowest mortality, Hawaii next, and California last, so that the further from the home culture, the greater the incidence of heart failure. The Americanization of the Japanese would of course introduce other factors such as a diet less friendly to good heart health. (22)

A similar effect of social factors on heart disease was shown in the Roseto study. Here there was a change in time rather than place with few confounding variables, the same small isolated community changed dramatically over time in incidence of heart failure in the same population as the societal influences changed. (23)

Roseto, Pennsylvania is a small community, primarily Italian that was studied over a number of years by Bruhn and Wolf. (24) The community was cohesive and it was thought that the 'safety net' (our words) effect of the tight community lead to reduced stress and, consequently, to a reduced incidence of heart disease. This is interesting in

that the Italians spring from the Mediterranean, not a location associated with reduced heart disease, and one that consumes a diet that is far from cardiac friendly.

To quote from Bruhn and Wolf: “From the beginning the sense of common purpose and the camaraderie among the Italians precluded ostentation or embarrassment to the less affluent, and the concern for neighbors ensured that no one was ever abandoned. This pattern of remarkable social cohesion, in which the family, as the hub and bulwark of life, provided a kind of security and insurance against any catastrophe, was associated with the striking absence of myocardial infarction and sudden death among those in the first five decades of life.” (24)

In *Society and Health*, Patrick and Wickizer write, "Roseto was characterized by ethnic and social homogeneity, close family ties, and cohesive community relationships..." and "In a 50-year comparison of mortality rates, Egoff and colleagues (1992) found a progressive rise in the mortality rate from myocardial infarction among Roseto men and women over the 30-year period between 1935 and 1964. After this period, a sharp increase occurred between 1965 and 1974, accompanying a decrease in social cohesion (Wolf and Bruhn, 1992), as did a similar increase in total mortality.” (25)

In summary, congestive heart failure is a multi-factorial disease complex that defies a simple description and cursory analysis. All related and associated factors and conditions are important to varying degrees in supporting cardiac health. Effective individual patient or larger population management of heart disease thus requires collecting detailed and continuing information on a comprehensive basis across many individuals. As most patients, especially the elderly, with congestive heart failure are treated by primary care physicians rather than cardiology specialists, it is especially important that subtle differences in patient physiology, presentation, and evaluation be clearly determined, recorded and analyzed. (8) Heart failure “has emerged as an epidemic health problem with major socioeconomic implications.” (26)

### **Quality of Life Factors for General Health**

Quality of Life is considered the broadest conception, encompassing all factors related directly and indirectly to health status. The primary modern proponent of the broader view of health within the concept of quality of life has been the World Health Organization (WHO). In its Constitution of 1948, WHO defined health as “a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity.” (27) (28)

Since the WHO Constitution, work in the United States on the more general conception of health was supported in the 1960's and 1970's by the National Center for Health Statistics, which sought a single index to judge health. (29) Research in Alameda County, California at that time was an attempt to define measurements of health for a captive population. This work in Alameda County was able successfully to associate mental health and social conditions with health in general, but did not achieve a single index of health. (30) (31)

Subsequently, Evans summarized similar research in Canada, an ongoing attempt to define the health of the population. His book, *Why Are Some People Healthy and Others Not*, viewed health in the larger sense to include social, environmental, economic and a

wide range of related topics. The sum total conception, similar to that of the World Health Organization, was quality of life of which health was a primary component. (32)

In the late 1970's and early 1980's researchers began to include health assessment and quality of life data in clinical trials. When new medications or treatment plans evolved, providers realized that the effects of such treatments on the more general quality of life, especially that related to health, was important and needed to be studied. Such work in congestive heart failure was summarized in 1984 in the book, *Assessment of Quality of Life in Clinical Trials of Cardiovascular Therapies*, which notes 10-20 major domains or elements of quality of life to be considered. (33)

Kindig, working in the United States, expanded on the work done previously, especially that of Evans and the group in Canada, and reiterated the 9 or more categories that comprise components of quality of life or health in general. These components included social, environmental, and economic as well as health indicators. These categories encompass the major physical health factors, including: disease, health care, health function, genetic endowment, physical environment, social environment, individual response, behavior, biology, well being, prosperity. Kindig considered how one might determine a population's health and what problems might be addressed. (34)

Most recently, the U.S. Department of Health and Human Services published the study Healthy People 2010, a manifesto on what is important in health in the United States and how progress might be made. (2) The goal of this document is to improve the quality and number of years of healthy life, applying a goal to the American people similar to the definition of health, within the more general quality of life scheme, as in the WHO Constitution.

Healthy People 2010 is a wide-ranging evaluation and lists 467 objectives in 28 focus areas that are considered vital to health, its definition, its monitoring, its modification and its improvement. To achieve the stated goal, these objectives and focus areas must be addressed. (2)

Among the 28 focus areas in Healthy People 2010, heart disease is clearly a key topic as it is a primary cause of mortality and morbidity. Any efforts to improve quality of life or extend quality of life years, requires an improvement in the condition of those patients with heart disease in general and congestive heart failure in particular. The aging population and the rising incidence of CHF will make heart failure ever more important in this discussion; as the elderly population will nearly double in the next several decades, CHF will become a problem of extraordinary proportions. (8)

Healthy People 2010 also lists indicators of health and risk factors. This list, entitled "Leading Health Indicators" includes: physical activity, obesity, tobacco, substance use, sexual behavior, mental health, injury and violence, environment, immunization, access to health care. These naturally have great overlap with the primary health factors related to congestive heart failure listed above. (2)

In a similar way, the Veterans Administration health system has begun a large medical practice reorganization, an attempt to bring best medical practices and outcomes to its population. The VA program entitled QUERI, lists 8 primary areas of focus, one of which is congestive heart failure. An aim of this program is to show improvement in patients' functionality and quality of life as a result of treatment pathways and the institution of best practices. Demonstrable improvements in quality of life are among the primary goals. (35)

## Quality of Life Questionnaires for General Health

There are more than one hundred general health status questionnaires, where the patient fills out a short paper form to record their health status. The best-known general health questionnaire is the SF-36, which grew out of work at the Rand Corporation in the late 1970's and 1980's. The Rand researchers, influenced by the work in Alameda County and inspired by the concept of an index for health, searched for a means to determine patient outcomes from disease and treatment as well as a means to monitor a specific disease.

After extensive research and work with a number of trial populations, they settled on a 36 short question form to be completed while waiting in a provider's office or while on the telephone with an examiner. The questions have been worded so that they can be easily and accurately answered by an ordinary patient, while a physician or other provider could interpret the answers. Complex statistical analysis of responses to the SF-36 is not ordinarily needed or required. (36) (37)

Other general health status questionnaires include the Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP), and numerous others that share several common characteristics. (38) (39) They are also short versions of 10-50 questions, since they are paper forms completed while patients wait in an office. This limits the number of questions to those that can be completed in less than about 20 minutes. Although there are many, literally a thousand quality of life estimates (40), the best known and most commonly used questionnaire remains the SF-36. (37)

As commonly used today, the SF-36 gives a general assessment of an individual's health status. Such instruments are used for population screening, or for monitoring particular details of interest. Most often, public health experts use these general health questionnaires to obtain baseline data, or academic and pharmaceutical researchers use them in clinical trials and new medication studies.

Health status questionnaires have been shown effective for predicting patient outcomes to treatment for severe conditions. For example, Bosworth describes a large VA clinical trial of 2885 patients using the SF-36 as a screening tool for patients about to undergo heart surgery. The patients were asked a question from the SF-36, "In general, would you say that your health is excellent, very good, good, fair, or poor?" The question scores were correlated with survival and outcome and there proved to be a strong relationship between self-rated health and subsequent coronary artery disease related mortality. (41)

Bosworth quotes the work of Mossey and Shapiro and the study in Manitoba that showed that elderly patients' self-ratings of health were more accurate in predicting 7-year survival than was the ratings of medical professionals. Their work described in the VA study above supported the findings in Canada. (41)

The Whitehall II study in Britain demonstrated that changes in health status over time was related to position in the civil service and economy. (42) This was a large trial with 12,000 patients and produced striking evidence that mortality was directly correlated with amount of environmental stress. That is, heart failure was highest at the lowest levels of the job hierarchy ("pressed by everyone") and lowest at the highest levels of the hierarchy ("pressed by no one"). (42)

Also writing about the results of Whitehall II, Hemingway specifically used the SF-36 to measure changes in health status over time. The Hemingway study shows that the SF-36, when applied to civil services as a study population in 1991 and 1993 and then again between 1995 and 1996, demonstrated a difference in health. The study population was a total of 8349 participants in the 1991 and 1993 and 7949 (of the 8349) participants in 1995/1996 completed the entire study. (43)

The SF-36 used in this fashion, as a monitor to demonstrate changes in health of large populations at risk, was confirmed as having validity. The SF-36 results showed a change in the health of the populations, as hypothesized, related to changes in age, employment grade and disease status. The authors also confirm that patients with both physical and mental health difficulties showed a significant decline in health over the study period as compared with patients who had either/or but not both physical and mental health problems. Socioeconomic status was inversely related to health: those in the lower levels of the socioeconomic scale had greater deteriorations in health as measured by the SF-36 as compared to patients at the upper ends of the socioeconomic scales. (42) (43)

A summary of the SF-36 question topics follows:

- 1-2 general health
- 3-12 bending and lifting
- 13-19 accomplishment of daily activities
- 20-22 pain syndromes
- 23-31 'pep', 'energy', 'calm', 'peaceful', 'worn out'
- 32 social activities
- 33-36 sicker or healthier than others
- 37 gender
- 38 age
- 39-41 depression

## **Quality of Life Questionnaires for Congestive Heart Failure**

Since treatments of congestive heart failure influence the quality of life of a patient, CHF specific questionnaires have been used in clinical trials. At least 10-20 general health factors are associated with CHF but the commonly used CHF specific questionnaires have usually focused on a few key clinical points in order to gather uniform and useful information. (1) (44)

Leidy, in 1999, reviewed health related quality of life (HR-QoL) questionnaires in congestive heart failure. She found 41 such studies using HR-QoL instruments published between 1990 and 1998. Most commonly, such questionnaires are used in conjunction with clinical trials that test the effectiveness of new medications or treatment plans. She also notes that HR-QoL relates to many domains including disease state, physical and social functioning, social interaction and emotional state. In the review, Leidy found that 30 of the 41 studies were trials evaluating the effectiveness of a medication; the remaining studies focused on physical exercise, nasal positive airway pressure, nurse case manager and primary care related quality of life. In summary, Leidy found that no single

general QoL measure dominated the area of CHF and that three-quarters of the studies were related to drug trials. (44)

Marwick did a study in 63 patients undergoing coronary artery bypass with a pre-operative assessment of heart failure. The Nottingham Health Profile (NHP), another general health questionnaire but here used for a particular disease class trial, was used in this trial and demonstrated, as it had in prior trials, that quality of life did improve in most patients after surgery. Marwick did note, however, that the improvement in quality of life did not correlate directly with the amount of viable myocardium. (45)

O'Leary describes another CHF disease specific questionnaire, the LVD-36 (left ventricular dysfunction questionnaire), which was used to monitor patients with congestive heart failure over time. In a cohort of 60 patients the LVD-36 questionnaire was able to show changes in health status when the questionnaire was repeated after 6 months, thus acting as a CHF disease specific health monitor. The authors describe the LVD-36 as short and simple and suggest that the instrument covers all the areas of life that are impaired by their disease. (46)

A more commonly used disease specific questionnaire for CHF is the Minnesota Living with Heart Failure questionnaire (LHFE). Rector describes the ease of use of this questionnaire to measure the therapeutic benefit of medications in a study conducted at eight different participating medical centers. LHFE was designed specifically to measure a patient's perception of heart failure and its effects on daily life; the validity of the use of LHFE in drug trials and in comparison with placebo has been confirmed. (47)

A new, CHF specific questionnaire, published in June 2000, is the Kansas City Cardiomyopathy Questionnaire (KCCQ) developed by Green and colleagues. (48) This questionnaire has two primary goals: to modify and guide patient care. The authors note that the KCCQ "is a valid, reliable and responsive health status measure for patients with CHF and may serve as a clinically meaningful outcome in cardiovascular research, patient management and quality assessment." The authors compared the CHF specific KCCQ with the more general SF-36 and with the CHF specific Minnesota Living with Heart Failure measures and believed that the KCCQ was more sensitive. As the authors also note, "In an era of rapidly expanding therapies for CHF, there is a need for robust mechanisms of quantifying the impact of new treatments on patients, their survival, their symptoms and their QoL." (48)

There is a difficulty in general with disease specific questionnaires, as Leidy notes and Green confirms, in that there is no specific reference standard for such questionnaires or for the collection and analysis of such disease specific data. (44) (48) Still, work such as the KCCQ and the Minnesota LHFE represent significant steps forward toward incorporating patient derived health status into clinical trials and subsequently into more routine clinical practice.

Like most disease-specific health status questionnaires, the KCCQ has a particular causal model built into its questions. Its clinical focus is primarily interested in fluid retention, or the perception of fluid retention, by the patient. Thus the questions center on assessing swelling of the ankles, shortness of breath, and fatigue. The questionnaire is thus most effective in patients with CHF who have systolic dysfunction, often with associated fluid retention, where the syndrome causes fluid congestion in the heart, lungs and peripherally. Unfortunately, this limits its utility in elderly patients, where the

enlarging majority of CHF cases occur and who frequently do not have fluid overload as a primary factor. (3)

As Rich writes, "Older adults are predisposed to developing CHF as a result of age-related changes in the cardiovascular system and the high prevalence of hypertension, coronary artery disease, and valvular heart disease in this age group. Although the fundamental pathophysiology of CHF is similar in younger and older patients, older patients are more prone to develop CHF in the setting of preserved left ventricular systolic function. This syndrome, referred to as diastolic heart failure, accounts for up to 50% of all cases of CHF in adults more than 65 years of age." (8)

A summary of the questions in the KCCQ follows:

- 1 dressing, yardwork, climbing
- 2 general about heart failure
- 3-4 leg swelling
- 5-6 fatigue
- 7-9 shortness of breath
- 10-11 general heart failure symptoms
- 12 enjoying life and
- 13 how you feel right now
- 14 feeling discouraged
- 15 general limitations of lifestyle

### **Expert Monitoring of Quality of Life for Congestive Heart Failure**

Cohn, in a review on managing CHF, writes that the best patient-derived information comes from long, in-depth interviews with providers, commonly physicians. (49) Yet, with the cost constraints and increasing population with CHF, physicians do not have the time available to obtain the in-depth information that a comprehensive program requires. Attempts to solve this problem of in-depth knowledge and information gathering from a particular patient have been addressed by the multi-disciplinary team approach or by disease state management (DSM) programs.

The use of multidisciplinary team interventions can help manage the elderly population with congestive heart failure. In practice, such teams rely on input from a variety of clinical areas and often focus on nurse case managers to interact directly with the patient, rather than having a physician conduct the in-depth interactions or interviews. A review by Rich notes that this approach has been uniformly associated with improved patient outcomes; one endpoint has been a reduction in recurrent hospitalizations in the elderly population studied with CHF. (3)

The core of the program focuses on the belief that a number of "behavioral factors, such as noncompliance with medications and diet, and social factors, such as social isolation, frequently contribute to early readmission" of elderly patients with heart failure. (3) The multidisciplinary program is able to prevent many readmissions by focusing on the behavioral and social issues noted, where improving these issues improves the patient's lifestyle. The healthcare team guides the patient in adhering to a wide variety of prescribed needs and follows the patient for evidence of any deviation.

An added benefit of this approach is the monitoring of patient compliance in the rigorous adherence to medication schedules and other prescribed treatments. Inadequate adherence to drug dosing is an understudied factor of vital importance to patients, such as the elderly with CHF, where optimization of a medication program can yield significant results. (50) (51) (52)

Other authors have confirmed the results of disease state management and multidisciplinary team interventions. Heidenreich established such a multidisciplinary program of patient education, home monitoring and physician interaction that was effective in reducing hospitalizations and total costs in a population of patients with heart failure. (53) Similarly, Kostis describes a program of “nonpharmacologic therapy” that was found to improve the exercise tolerance and “quality of life” of patients with congestive heart failure. (54)

These studies confirm that health status and quality of life can be improved, particularly via lifestyle modifications rather than just with pharmacologic treatments. But the programs that they describe are cost intensive, as indicated by their limited enrollment under the auspices of research programs at academic medical centers. Even without physician involvement, specialized experts are needed.

The dilemma remains of how to apply such programs over the vast population of elderly, with the burgeoning growth in congestive heart failure. It is not feasible to have such programs in place for each and every individual with heart failure. The multidisciplinary team programs are labor intensive and costly, dependent on highly trained nursing personnel. Even with the introduction of such an expensive program, underserved populations such as rural areas and inner city locations would be untouched.

### **Population Monitoring of Quality of Life for Congestive Heart Failure**

Rich, Heidenreich, Kostis and others demonstrate the vital importance of information and interaction with patients about many issues not usually noted in the medical record, yet important in enabling the improvement in a patient’s health and quality of life. Their efforts deserve a solution that can be applied to large numbers of patients in an economically feasible fashion, understanding the limited number of case managers.

The multidisciplinary team represents an ongoing, personal and interactive approach to obtaining patient derived data on a great range of vitally important topics. Virtually all of the health indicators listed in Healthy People 2010 can be addressed in such a manner, to track the WHO general conception of health. A myriad of factors touch upon congestive heart failure and associated diseases, such as smoking, exercise, diet, the environment social support, medication compliance and the like. Trained experts can measure and monitor all of these factors in the progress of disease across time.

Health status questionnaires, whether more general or related to a specific medical condition, have been shown to be of value and to produce consistent results. Patients can by themselves provide a gross description of their health status, without the intervention of a medical professional during the collection process. In simplest form, the SF-36 is used in trials of new drugs or for comparative medication trials. It gives a broad measure of health status of a cohort of patients in order to assess a change over time or as a result of an intervention. The intent in these cases is clearly to show that a particular

medication may have a positive medical effect without causing an associated deterioration in general health status or quality of life.

Similarly, disease specific health status questionnaires, such as the KCCQ, have been repeatedly demonstrated to be important and yield valid results when comparing cardiac medications or treatments. Each such instrument provides more detailed information about the patient's condition than could a general health questionnaire. However, the short length of the specific questionnaire necessarily requires it to focus on a particular clinical model. Surveying the health of a particular individual requires choosing the particular model or models appropriate for the current situation.

The problem becomes, then, how to take the valid results of an SF-36 type instrument and apply it to a large population, but at the level of detail of the multidisciplinary team's nurse case managers in the daily/weekly interactive fashion described. The primary functions of the nurse case managers are to screen patients and to monitor them, and it has been shown that the SF-36 methodology is a valid screen and monitor as well. To match the functionality of a nurse case manager, it would be necessary to utilize many different questionnaires, to measure all the different conditions and all the appropriate models for this particular patient in this particular situation.

A health status or quality of life program that could monitor the entire range of health factors could achieve results such as that of the multidisciplinary team but on a larger scale if such a program could be applied to a much greater population. Yet, Rich's work remains a model used by about 100 patients as it is so labor intensive and relies on the expertise of the nurse case managers. (3)

A health status, or quality of life, questionnaire such as SF-36 can be effectively applied to populations of 10,000 patients, such as in the Whitehall study. (43) For the multidisciplinary team to achieving this factor of 100 in scale would require considerably more financial and labor expertise than seems feasibly available for a process involving human experts.

Handling the entire population of patients would require supporting another factor of 100 in scale, to handle millions of patients. For example, it is estimated that 11-12% of those over the age of 40 have heart disease (6) and that more than 4,800,000 Americans have congestive heart failure. (55) With the aging population, the increasing incidence of congestive heart failure and the diminishing mortality from coronary artery disease, CHF is emerging as a major problem. A new technology for healthcare infrastructure is necessary to support this scale of health monitoring.

### **Internet Health Monitors across Whole Populations**

We propose a new healthcare infrastructure, called Internet Health Monitors, which can support health monitoring across a whole population. (56) The Internet is used to provide interactive questionnaires, which individual patients answer in their own homes. The questions are chosen adaptively for the particular patient and their particular condition from the entire range of possible questions, thus solving the major problem of the quality of life questionnaires. (57)

These computer-based health monitors are similar in function to a heart monitor, which enables an individual patient to generate a database to track personal cardiac function and seek treatment when the performance, or perception of performance, falls

outside safe parameters. In the more general health case, the patient must interact with a tracking system to record personal health parameters on a continual basis.

The self-care descriptions of health parameters can then be used to provide individualized treatments. During the course of a chronic illness, for example, communications between monitors and healthcare providers could result in treatments rapidly varied to match the illness' episodic nature.

The key to developing a national system for health monitors is to fully utilize modern computing and communications technology. Unlike a paper questionnaire, an electronic questionnaire consists of questions chosen dynamically from a much larger collection covering the full range of general health. These dynamic questionnaires can be customized to a particular individual in a particular health condition. The answers to these personal questions construct a detailed historical database for the health status of an individual.

The rise of the Internet has made it economically feasible to support national-scale health monitors from home computers. Personal computers are now widely enough deployed throughout the general public that millions of Americans routinely browse information on the Web. According to national surveys, healthcare is the single most referenced topic, with some two-thirds of users having accessed such information.

A Harris Poll in March 2000 estimated that 70 million Americans accessed health information on the Web in 1999. The percentage of Internet queries for heart-related topics and heart disease was 8%. Clearly, millions of heart patients already use the Internet for health information.

The Internet provides the technology, for the first time, to record continuously an individual's health, via direct interaction with each patient. (58) Surveys indicate that many elderly persons already use the Internet from their homes and that this usage will increase as the baby boomers age. (59) For example, the CHES project has shown that elderly women with breast cancer are willing to carry out daily interactions over the Net to read targeted brochures and participate in chat groups, even with no prior computer experience. (60) (61)

An Internet Health Monitor is an interactive program used by each individual to generate a daily record of personal health parameters. (56). By daily interaction with dynamic versions of traditional questionnaires, monitoring can be done of an individual patient's varying ability over time to cope with a disease. During each session, the patient can answer a limited number of questions, which are chosen from the master collection based on their previous interactions. They can interact with a web form on a daily basis, for example, using current technology.

The master collection of health status questions can cover the full range of health indicators contained in Healthy People 2010. It is initially developed by merging the questions from the most representative of the general health QoL questionnaires, such as SF-36, with the questions from the full spectrum of disease specific questionnaires, such as KCCQ. This process of monitoring complete health via combination of general and specific questionnaires has been previously proposed, (62) but the technology to implement it is just becoming available as standard Internet infrastructure. Dynamic variations can be added to account for time factors and disease progression, e.g. of changes since last session.

The existing questionnaires need to be supplemented to achieve the requisite level of detail for specific conditions. The interview records and case manager processes of the multidisciplinary teams, such as those for congestive heart failure discussed above, can be mined for daily and precise health status questions. This mining process is similar to the generation of an expert system specifically for CHF, for example. An expert system is a software program that uses knowledge rules gathered by interviewing subject matter experts, to advise non-experts on appropriate courses of action.

An Internet Health Monitor generates a patient record at a detailed and daily level for each individual. Once many patients interact with health monitors, these records can be combined into a national database of health status across individual patients. A major use of such a national database is to support physicians in prescribing treatments for a patient, by examining treatment patterns of cohorts of similar patients in the database.

Locating similar cohorts requires the use of sophisticated statistical matching techniques, such as Self-Organizing Maps (63) or Concept Co-occurrence (64). However, the health care providers need only use the matching software, not understand the algorithms that are implemented. The underlying technology would be embedded within the healthcare infrastructure for Internet Health Monitors.

Periodically, determined by medical parameters and health plan factors, trained professionals adept at such analysis would review this pattern data. This record of a patient's condition and of a disease's characteristics would identify changes that might be of importance, when early intervention by a health care professional is recommended. Such a partnership between patients and physicians, supported by modern information technology, will lead towards effective population management of congestive heart failure.

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## **Appendix: Technologies for Implementing Internet Health Monitors**

Many industries have undergone fundamental changes as a result of the digitalization of data. To name just several of the best known examples: banking and the ATM technology, airlines and automated reservations, the stock exchange and Internet trading. The list goes on. In each instance, changes in information technology profoundly altered the relationship between individuals and the bodies with which they were interacting. Medicine is a much more complex interaction than the examples above; consequently, it will take considerably longer to apply digitalization and electronic interchange in an acceptable and accepted format. The following is a short history of the developments in information science, which are leading to the imminent application of monitors to patient populations.

A decade of research by Schatz and his collaborators has developed the necessary technologies for the underlying information infrastructure. These technologies demonstrate that it is possible for patients to specify their health status from their own homes, creating local databases, and that physicians can search across the local databases, as though these constitute a single national patient database.

The Worm Community System (WCS) was a national model project in the early 1990s (65,66). It demonstrated that a national federated database was technologically feasible. That is, a community of scientists could individually enter data from their own laboratory into a local database, then collectively access the community database composed of the individual databases across the Internet.

The WCS was the flagship project in the NSF National Collaboratory program and developed custom software to support the national database in pre-Web days. The initial software was based upon the Telesophy System built by Schatz in the late 1980s at industrial research laboratories. Telesophy was also the local inspiration at the National Center for Supercomputing Applications for Mosaic, which catalyzed the Web and spawned Netscape, through Schatz's role as scientific advisor for information systems at NCSA (67,68).

The WCS users were molecular biologists who studied the nematode worm *C. elegans*, during the period when the worm became the model for the Human Genome Project. Data entry was supported to correspond with the structure of the desired data, such as genes, clones, and sequences. These databases were interlinked with documents such as biological literature and conference proceedings.

WCS supported federated search, where all the individual data sources could be logically searched as though they constituted a single physical database. The method of search was syntactic in nature. Thus a user could search for "mechanosensory" across data sources for genes, clones, and sequences, and text sources for journals and newsletters. The difficulty was that not all data items, which discussed the concept of mechanosensory, actually contained the word "mechanosensory".

Further research has made concept search technologically feasible. The work of Schatz and colleagues in the late 1990s has pioneered the information infrastructure for semantic indexing. Flagship projects in the NSF Digital Library Initiative and the DARPA Information Management program developed the Interspace Prototype (69,70).

The Interspace software environment can process documents from any subject area, automatically building semantic indexes that can be used for concept navigation across

data sources. The indexing is based upon the contextual co-occurrence of phrases within the document collection, and the user can interactively select related phrases from those, which commonly occur together. The practical utility of such concept navigation has been demonstrated by indexing all of MEDLINE, which covers the entire biomedical literature (71,72).

The Interspace Prototype provides semantic clustering of similar groups of documents. (73) A user can interactively examine clusters of related documents to quickly locate those relevant to a particular situation. The clustering relies on the semantic indexing, which operates automatically on the document collections. The technologies can thus scale to large numbers of collections, each containing the documents of some special community.

The Interspace Prototype was designed as a generic version of the Worm Community System. (74) It federates many local sources into a single global source. Post-web, the technology is ready for specifying data entry in structured format into local databases.

The Interspace Prototype is at the same state of maturity as the Telesophy Prototype just before NCSA Mosaic catalyzed the Web. This means that the global information infrastructure will very shortly support semantic indexing as a standard service. Thus, concept navigation across community sources will be routine in the foreseeable future. This implies that the patient data from health monitors could be effectively analyzed across the Internet.

To test this assertion, the authors have been building prototypes of Internet Health Monitors, in collaboration with the College of Medicine at the University of Illinois and the Health Alliance HMO and the Carle Foundation Hospital. Several versions of initial prototypes have been implemented.

A preliminary plan exists for a formal clinical trial within Champaign County. See [www.canis.uiuc.edu](http://www.canis.uiuc.edu) under Medspace for further information about the prototypes and the plans. However, the major effort required for a full prototype and trial, similar to those for the Worm System or the Interspace, has not yet been mounted.

An earlier prototype of quality of life questionnaires was used to provide interactive coverage across general health status. These 20 questionnaires provided some 500 questions across the range of WHO health factors. The questions were categorized using the schemes of Evans and Kindig, for guidance during the question-asking sessions.

In early trials, it was discovered that a single categorization scheme was not adequate to assess patient health status. An interactive categorizer has now been developed to enable physicians to provide multiple categorization schemes for different points of views in asking and interpreting the questions.

Congestive Heart Failure is a promising area to test the clinical effectiveness of Internet Health Monitors. We are re-categorizing, for the interactive categorizer, the questions from the general-purpose quality of life questionnaires and supplementing these with questions from special-purpose questionnaires specifically relating to CHF.

Our plan for initial clinical trials is to work closely with an existing group of expert nurses, such as those described above by Rich and his colleagues who have implemented multidisciplinary teams to track and monitor patients with congestive heart failure. The knowledge of these nurses will be mined to provide the more detailed levels of questions necessary for clinical effectiveness.

The goal is that health monitors will supplement the existing activities of the expert nurses in multidisciplinary teams. The health monitors can frequently screen the patients for routine conditions and generate multi-patient databases, which the nurses can analyze for unusual conditions. With the computer support for routine monitoring, the nurses should be able to devote their time to much larger populations and to concentrate on more severe conditions or the more personalized training that requires their expertise. Expert physicians would be able to follow the larger population and work with an extended network of teams and nurses.

Such clinical trials will test whether computer augmentation can support significant increases in the caseloads for expert nurses. As the information infrastructure supporting health monitors becomes standard nationwide, a provider pyramid for supporting population management of heart failure can be implemented. The bulk of routine interactions can be handled by augmented nurses and home monitors.

This computer augmentation should free the expert physicians and other trained professionals to handle the most difficult situations and to manage the delivery of medical care. Such infrastructure support for population management of chronic illness may enable both physicians and patients to prosper as the scale of heart failure increases with the aging population.

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