



2008

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Corrine Jurgens

Jom Suwanno

Barbara Riegel

University of Pennsylvania, briegel@nursing.upenn.edu

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Recommended Citation (OVERRIDE)

Jurgens, C., Suwanno, J., & Riegel, B. (2008). Quality of Life in Heart Failure. In Beattie, J. & Goodlin, S. (Eds.), *Supportive Care in Heart Failure*, 147-158. Oxford University Press.

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Quality of Life in Heart Failure

Abstract

Chronic illnesses such as heart failure (HF) are known to impair quality of life. HF, in particular, is associated with unpleasant symptoms, limitations in activities of daily living, and increased risk of hospitalization for symptom management.¹ The effects of chronic illness on symptoms, functioning, and the risk of hospitalization decrease quality of life in persons with HF.

Keywords

heart failure, quality of life, interventions, physical dimension, emotional dimension, social functioning, medical therapy, disease management

Disciplines

Cardiology | Cardiovascular Diseases | Circulatory and Respiratory Physiology | Medical Humanities | Medicine and Health Sciences | Nursing

Quality of life in heart failure

Corrine Jurgens, Jom Suwanno, and Barbara Riegel

Chronic illnesses such as heart failure (HF) are known to impair quality of life. HF, in particular, is associated with unpleasant symptoms, limitations in activities of daily living, and increased risk of hospitalization for symptom management.¹ The effects of chronic illness on symptoms, functioning, and the risk of hospitalization decrease quality of life in persons with HF.

Clinicians, patients, and their families know that living longer is not necessarily desirable if quality of life is poor. Thus, quality of life has emerged as an important factor in both the delivery of health care and in health-care research. In health-care research, quality of life measures are often included when assessing the effectiveness of interventions or therapies. These measures are integral, because testing new therapies includes evaluating efficacy *and* patients' subjective judgments of whether their lives are improved.

A controversy within the HF field is the effectiveness of interventions in improving quality of life. For example, some believe that disease management improves quality of life,² while others disagree.³ This controversy is probably related to the lack of a universally accepted definition of quality of life, which has hampered both measurement and comparisons among studies.^{4–6} Often, in studies of quality of life, a definition is omitted, related concepts are substituted, or measurement is limited to one or more components of the construct.⁷ The purpose of this chapter is to lend some clarity to the discussion of quality of life in HF. To do so, we will explore definitions of quality of life, review the literature on the effect of HF on quality of life, and end by summarizing what is known about the effect of interventions on quality of life in persons with HF.

Defining quality of life

Widespread multidisciplinary use of the term quality of life⁵ and its complexity⁶ have been suggested as reasons for the lack of a consensus on a definition of quality of life. Initially only objective social indicators like type of housing and educational level were thought to influence quality of life. However, these factors accounted for only 15% of the variance in quality of life for an individual. Subjective indicators such as satisfaction with life, happiness, and well-being are now believed to be important dimensions; these psychological factors account for over 50% of the variance in quality of life.⁸ In one study of quality of life in HF, the subjective variables perceived health status and perception of symptom status influenced quality of life more than objective measures of functional status.⁹

Concept analysis has been used in an effort to further clarify the construct of quality of life.⁴⁻⁶ In one such concept analysis, Meeberg⁴ defined quality of life as:

... a feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated. Other people from outside that person's living situation must also agree that the individual's living conditions are not life-threatening and are adequate in meeting that individual's basic needs. [p. 37]

Not everyone includes both subjective and objective indicators and some do not limit the definition to those able to provide self-report data. For example, Haas⁶ defined quality of life as:

... a multidimensional evaluation of an individual's current life circumstances in the context of culture and value systems in which they live and the values they hold. Quality of life is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions. In some circumstances, objective indicators may supplement or, in the case of [people] unable to subjectively perceive, serve as a proxy assessment of quality of life.[p. 219]

In this definition, subjective indicators are weighted heavily and quality of life is not limited to the mentally alert. An important contribution of this definition is Haas' differentiation of quality of life from the related concepts of well-being, satisfaction with life, and functional status. Table 8.1 shows some other definitions of quality of life using variations of the components reflecting physical, emotional, and social function.

Health-related quality of life is more restrictive than global quality of life, conceptually limiting the components or factors to those related to health and health care. Other factors such as income and education may be indirectly related to health but are not included in the definition.^{10,11} Health-related quality of life measures are useful in health-care research because they reflect patient experiences and health status resulting from health care.

Although quality of life has been defined in numerous ways, generally most agree on the following. Quality of life as a construct is complex, multidimensional, and dynamic. Subjective self-report of quality of life by individuals is preferred over the views of others or objective measures alone.^{12,13} The complexity and multidimensional characteristics are reflected in the physical, psychological, and social domains cited both explicitly and implicitly in several models of quality of life.^{6,11,12,14,15}

Models of quality of life

Domains of quality of life have been identified and models explaining their relationships have been proposed. Although terminology varies from author to author, the domains are similar and incorporate both subjective and objective indicators.^{6,11,12,14,15} Three models were chosen for discussion; one is a global quality of life model and the other two are health-related quality of life models.

The model by Haas⁶ reflects a global perspective where subjective well-being is considered the primary indicator of quality of life. The objective component is functional status. Functional status is not limited to physical functioning, but refers to all

Table 8.1 Definitions of quality of life

Author	Definition
World Health Organization (1993) ⁵⁷	'... individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad ranging construct affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment.'
Ferrans and Powers (1985) ⁵⁸	'satisfaction of needs' where satisfaction is defined as the 'perceived discrepancy between aspiration and achievement, ranging from the perception of fulfillment to that of deprivation' and need was defined as 'the amount of a particular reward that a person may require.'
Meeberg (1993) ⁴	'... a feeling of overall life satisfaction, as determined by the mentally alert individual whose life is being evaluated. Other people from outside that person's living situation must also agree that the individuals living conditions are not life-threatening and are adequate in meeting that individual's basic needs.'
Guyatt (1993) ¹⁰	'Health-related negatively valued aspects of life, including death, to more positively valued aspects of life such as role function or happiness.'
Osoba (1994) ⁵⁹	'A multidimensional construct encompassing perceptions of both positive and negative aspects of physical, emotional, social, and cognitive functions, as well as the negative aspects of somatic discomfort and other symptoms produced by a disease or its treatment.'
Wilson and Cleary (1995) ¹¹	'Subjective well-being related to how happy or satisfied someone is with life as a whole.'
Haas (1999) ⁶	'... a multidimensional evaluation of an individual's current life circumstances in the context of culture and value systems in which they live and the values they hold. Quality of life is primarily a subjective sense of well-being encompassing physical, psychological, social, and spiritual dimensions. In some circumstances, objective indicators may supplement or, in the case of [people] unable to subjectively perceive, serve as a proxy assessment of quality of life.'

dimensions of life—physical, psychological, and social dimensions—common to several models, plus a spiritual dimension. The indicators of quality of life (subjective well-being and objective functional status) are interrelated with all of the dimensions.

A health-related quality of life model useful for testing the effects of HF and medical care on patients' lives was proposed by Rector (Fig. 8.1).¹⁵ In this model 'symptoms, functional status, and psychological distress are distinct, but interrelated phenomena that mediate the effects of HF pathophysiology on a patient's quality of life' [p. 173]. Symptoms are abnormal states produced by the pathophysiology and are subjectively perceived by the patient. Functional status is broadly defined to include physical, social, and emotional functioning. Psychological distress refers to negative psychological responses to illness and is related to symptoms and functional status.

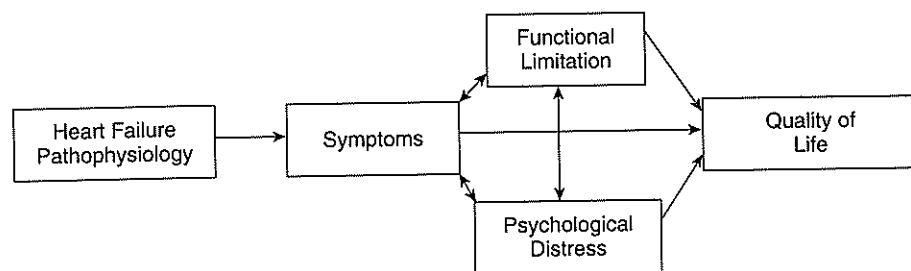


Fig. 8.1 Rector's model of quality of life (Reprinted from Rector¹⁵, copyright ©2005 Elsevier Inc. With permission from Elsevier.)

Wilson and Cleary¹¹ integrated clinical and social science models in their health-related quality of life model depicted as a continuum that begins with biological and physiological variables sequentially leading to symptom status, functional status, general health perceptions, and quality of life. Each preceding component is thought to influence the subsequent one, culminating in overall health-related quality of life. Characteristics of the individual and the environment are included in the model but were not discussed by the authors. Similar to Rector's definition, symptoms were defined as the patient's subjective perception of abnormal physical, emotional, or cognitive states. Functional status was defined as the ability to perform tasks in multiple domains (physical, social, role, psychological).

In a revision of Wilson and Cleary's model, Ferrans and colleagues¹⁴ described characteristics of the individual and environment omitted in the original publication of the model. Characteristics of the individual were defined as demographic, developmental, psychological, and biological factors that influence health. Environmental characteristics were categorized as social or physical. Social environmental characteristics acknowledge the influence of family, friends, and health-care providers on health. Physical environmental characteristics such as the home, neighborhood, or workplace factors can influence health. Arrows from characteristics of the individual and environment to biological function were added to demonstrate their influence on that domain.

A major limitation of these models of quality of life and other published taxonomies is the use of several terms with similar meanings. Conceptually unique terms like life satisfaction, subjective well-being, health status, and satisfaction of needs are used synonymously and interchangeably with quality of life. Cultural considerations further complicate the quest to identify a universal definition of quality of life. Culture contributes in important ways to quality of life,¹⁶ but only Spilker's model¹⁷ (Fig. 8.2) illustrates how patient values, including those influenced by culture, influence relationships between medical treatments and quality of life.

Effect of HF on quality of life

The common dimensions of quality of life in all the models reviewed are physical, emotional, and social function. In this section, we describe the effect of HF on each of

these dimensions. The physical dimension includes biological or illness characteristics, symptoms, and functional status. The emotional dimension includes the psychological response to HF. Social functioning includes sociodemographic factors, including cultural and environmental aspects.

Effect of HF on physical function

In persons with HF, symptom burden and functional limitations are the most significant predictors of quality of life.^{18,19} Common and bothersome symptoms include lack of energy, fatigue, shortness of breath, swelling, difficulty breathing while sleeping supine, and coughing.^{20,21} Patients with HF experience an average of 3 to 13 symptoms.²² In one study, more than 90% of 139 patients had multiple symptoms; 15% had every symptom queried about. An average of 7.2 symptoms was identified on admission and 4.2 symptoms 6 weeks after a HF hospitalization. Initially, shortness of breath was the primary symptom but by 6 weeks, fatigue was most common and troubling. Low vigor scores were similar to those with cancer.²²

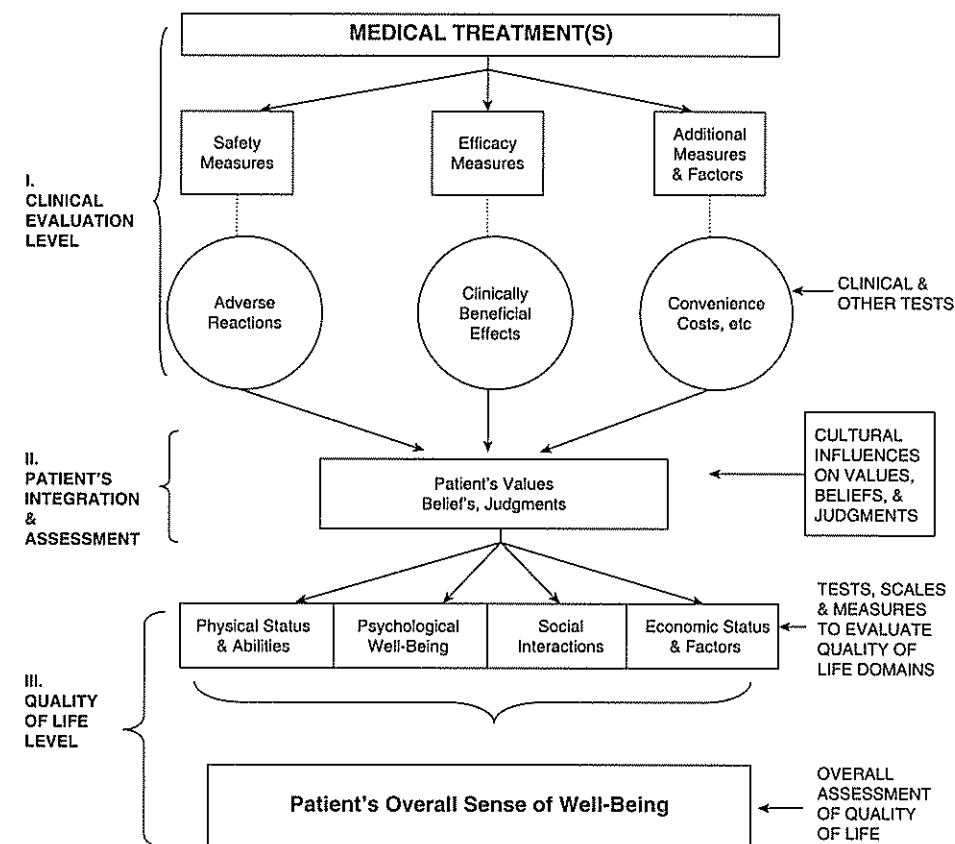


Fig. 8.2 Model of how clinical aspects of efficacy (i.e. benefits), safety (e.g. adverse reactions) or other factors are integrated through the patient's values, beliefs, and judgments to influence his or her quality of life. (Reprinted from Spilker¹⁷ with permission from Lippincott, Williams, and Wilkins.)

HF patients who are asymptomatic [New York Heart Association (NYHA) functional Class I] have better quality of life than those with symptoms and impaired functioning (NYHA Class II–IV).²³ Patients with less severe symptoms have a better mood and higher life satisfaction than those with more severe symptoms.²⁴ Those with poor physical functioning have worse health outcomes, including quality of life.²⁵ These symptomatic, functionally compromised patients frequently delay returning to normal daily, work, and social activities.²⁶

Effect of HF on emotional function

HF causes anxiety, depression, and overall emotional distress (for a detailed discussion see Chapter 15). In a recent study of 100 outpatients with systolic HF drawn from a community HF program in the United Kingdom, the prevalence of anxiety was 18.4% by clinical diagnostic interview.²⁷ Whether or not anxiety is higher in persons with HF than other cardiac populations or the general population is unclear. One study found mean anxiety scores in HF patients to be only slightly higher than the general population²⁸ but another study found that anxiety was similar in the patient groups but higher than healthy older adults.²⁹ Predictors of anxiety include a history of mental illness, comorbid physical illness (diabetes and angina), and NYHA class. Specifically, anxiety is probably higher in patients who are relatively more functionally compromised (NYHA Class III/IV) compared with those without as much functional compromise.²⁸

The prevalence of depression has been estimated to range from 13% to 77% in patients with HF, depending on the timing and manner in which depression is measured.^{30,31} Patients with HF in whom depression is assessed during hospitalization have higher rates of major depression than those assessed in an outpatient setting (30% to 75% of hospitalized patients^{22,30} vs 24% to 42% in outpatient settings³²). Depression in HF is associated with the severity of illness, functional capacity, and symptom severity. Carels³³ suggests that depressive symptoms may have a greater impact on quality of life than severity of cardiac dysfunction or functional impairment.

Effect of HF on social function

Some investigators have suggested that women with HF have worse quality of life than men,³⁴ but other investigators have found few clinically significant gender differences.³⁵ In another study, women with HF had significantly better health perceptions and constructed meaning than men.³⁶ Age of onset may explain this discrepancy. In one study, women under the age of 65 years had poorer quality of life compared with their male counterparts in the same age group.³⁷ The authors suggested that the interaction of age and gender in relationship to quality of life may be related to baseline psychological state or the burden of other illnesses. For example, young women may have family and work responsibilities that have already stretched their coping abilities. Diabetes and hypertension are common causes of HF in younger women. When HF is added to existing social burdens and/or other chronic conditions, a measurable influence on quality of life may become evident.

Social functioning encompasses the ability to maintain social and work activities. Few investigators have specifically examined these outcomes in persons with HF. Carels *et al.*³⁸ found a link between physical symptoms and psychosocial functioning, including social conflict. Friedman and King²⁴ found that HF patients with higher levels of emotional support had higher life satisfaction than those with lower levels of emotional support. Others have found that changes in perceived social support significantly predicted changes in quality of life.³⁹ Again, in this study, there was a significant interaction of gender by age, with younger men (<65 years) perceiving less support than older men (≥65 years) and women in general. It should be noted, however, that the link between social support and quality of life is neither strong nor consistent.⁴⁰

Surprisingly few investigators have studied the effect of cultural factors on quality of life. We have⁴¹ illustrated that quality of life improved significantly more following an acute HF hospitalization in Hispanics compared with a matched sample of non-Hispanic Whites. No other comparisons of ethnic cultural groups were located in the literature. Cultural aspects of care are reviewed in Chapter 25.

Even fewer investigators have assessed return to work in persons with HF. It is known that HF outcomes are poorer in patients in the low socioeconomic status groups.⁴² Research on the influence of return to work on quality of life in persons with HF is greatly needed.

Quality of life measures

Several HF-specific quality of life instruments have been developed and tested in response to the need for clinically relevant measures which are sensitive to clinical change. The most commonly used instruments are the Chronic Heart Failure Questionnaire, the Minnesota Living with Heart Failure Questionnaire, and the Kansas City Cardiomyopathy Questionnaire.^{10,43,44} These instruments differ on their clinical responsiveness and the range of clinical domains addressed.

The Chronic Heart Failure Questionnaire tests the domains of dyspnea, fatigue, and emotional function.¹⁰ Patients identify five frequent activities associated with shortness of breath that are important in their daily lives. These activities are used to evaluate their effect on the three domains of social, emotional, and physical quality of life using a seven-point scale.

The Minnesota Living with Heart Failure Questionnaire is the most commonly used quality of life measure in patients with HF.⁴⁴ This instrument is a 21-item scale focusing on patients' perceptions of the effects of HF on their lives. It has two subscales testing physical and emotional domains of quality of life using a six-point scale. The social domain is evident in specific items.

The Kansas City Cardiomyopathy Questionnaire is a 23-item instrument that tests physical limitations, symptoms, social interference, and self-efficacy. Symptoms are independently quantified in relation to frequency, severity, and stability.

All of these instruments are reported to be more sensitive to clinical change than generic quality of life measures. The Chronic Heart Failure Questionnaire may be particularly useful

in small samples because a smaller change in score is needed to detect a clinically important improvement than that of the Minnesota Living with Heart Failure Questionnaire.⁴⁵ The Kansas City Cardiomyopathy Questionnaire is substantially more sensitive to clinical change than generic quality of life measures or the Minnesota Living with Heart Failure Questionnaire.⁴³

Increasingly, providers are administering one of these HF-specific measures to patients in their clinical practices and tracking their quality of life over time. Others who want to avoid the burden of scale completion simply ask their patients to rate their overall quality of life on a scale from poor to excellent. Regardless of the approach used, some assessment of this penultimate indicator of treatment effectiveness is needed.

Effectiveness of interventions in improving quality of life in HF

In this section we briefly review studies of the effectiveness of various medications and disease management approaches on quality of life. Most studies of the effect of angiotensin-converting enzyme (ACE) inhibitors found an improvement in quality of life associated with this medication.⁴⁶ It should be noted, however, that in most of those studies, quality of life was defined as physical functioning (e.g. symptoms, functional class). Some studies have found little or no specific benefit of ACE inhibitors on quality of life.^{47,48}

The data on the effect of β -blockers on quality of life is also inconclusive. In a review of 10 studies that measured quality of life with one of two specific instruments (Quality of Life Questionnaire in Severe Heart Failure; Minnesota Living with Heart Failure Questionnaire), only three reported significant improvements in quality of life. Using a single-question global assessment, improved quality of life was found in five of seven studies.⁴⁹

Recent meta-analyses summarizing the effect of disease management have been unconvincing about its effect on quality of life. Six of the 18 studies reviewed by Phillips *et al.*⁵⁰ assessed quality of life and all six found improvements. The pooled effect showed a 13.5% improvement in quality of life. McAlister *et al.*⁵¹ reviewed 29 studies, 18 of which assessed quality of life. Seven of those 18 studies found significant improvements in quality of life and two more found a 'trend' toward improvement. A trend toward improved quality of life was also noted by the authors of another meta-analysis reviewing eight trials, four of which assessed quality of life.⁵² Two of these four found a significant improvement in quality of life. Finally, Whellan *et al.*² reviewed 19 trials and concluded that there was 'consistent improvement in quality of life'; the number of trials on which this conclusion was based was not specified and no data were provided.

It should be noted that a publication bias could be in effect with the disease management literature. We have examined quality of life in each of our HF disease management studies, but rarely included these data in our results.^{53–55} In each trial we found a consistent picture; as shown in Fig. 8.3, quality of life improved over time after hospital discharge when measured using the Minnesota Living with Heart Failure Questionnaire, regardless of the group (intervention or usual care) to which the patient was assigned. This consistent result may reflect a relatively insensitive measure⁵⁶ or a true

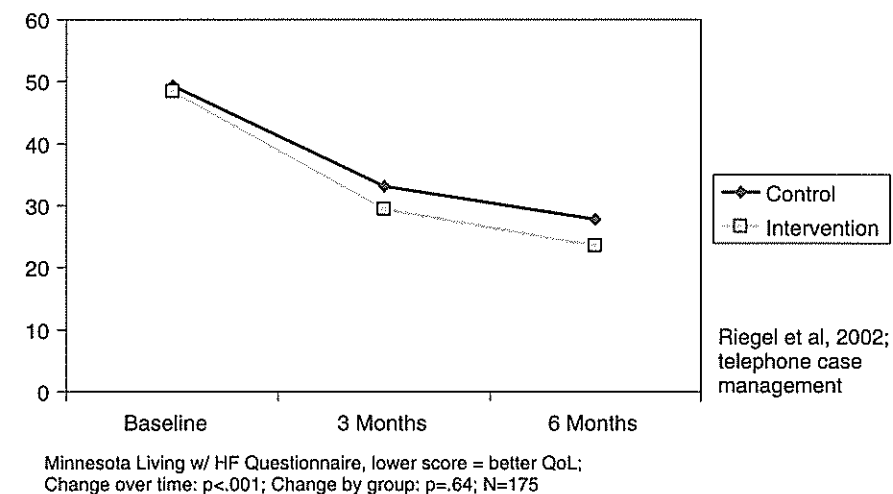


Fig. 8.3 Changes in quality of life over time by group.

observation that disease management is not sufficiently powerful to influence quality of life. Others have substantiated this finding of a lack of effect on quality of life with disease management.³ A meta-analysis of the effect of HF disease management on quality of life would be an extremely valuable contribution to the literature.

Conclusion

In this chapter we have described various models and definitions of quality of life. Quality of life was defined as a complex, multidimensional, and dynamic construct. Most models specify the domains of physical, emotional, and social functioning. Health-related quality of life was differentiated from the global concept as those aspects of quality of life specific to health. The extant literature was used to support our conclusion that HF has a negative influence on all aspects of quality of life, although more research is needed on social functioning.

Some evidence suggests that optimal medical therapy and perhaps disease management can improve quality of life, but many of the studies are limited by failure to define the construct and measure it in its complexity. A publication bias may be evident, with negative trials going unreported. Although quality of life has been measured relatively more commonly in recent years, trials are still conducted that fail to include this essential outcome. Further research is greatly needed to identify interventions that effectively improve the quality of life for persons with HF.

References

1. Bennett SJ, Cordes DK, Westmoreland G, Castro R, Donnelly E (2000). Self-care strategies for symptom management in patients with chronic heart failure. *Nurs Res* 49: 139–45.
2. Whellan DJ, Hasselblad V, Peterson E, O'Connor CM, Schulman KA (2005). Meta-analysis and review of heart failure disease management randomized controlled clinical trials. *Am Heart J* 149: 722–9.

3. Smith B, Forkner E, Zaslow B *et al.* (2005). Disease management produces limited quality-of-life improvements in patients with congestive heart failure: evidence from a randomized trial in community-dwelling patients. *Am J Manag Care* 11: 701–13.
4. Meeberg GA (1993). Quality of life: a concept analysis. *J Adv Nurs* 18: 32–8.
5. Farquhar M (1995). Definitions of quality of life: a taxonomy. *J Adv Nurs* 22: 502–8.
6. Haas BK (1999). A multidisciplinary concept analysis of quality of life. *West J Nurs Res* 21: 728–42.
7. King LA, Napa CK (1998). What makes a life good? *J Pers Soc Psychol* 75: 156–65.
8. Day H, Jankey SG (1996). Lessons from the literature: toward a holistic model of quality of life. In: *Quality of Life in Health Promotion and Rehabilitation* (ed. R Renwick, I Brown, M Nagler), pp. 39–62. Thousand Oaks, CA: Sage.
9. Heo S, Moser DK, Riegel B, Hall LA, Christman N (2005). Testing a published model of health-related quality of life in heart failure. *J Card Fail* 11: 372–9.
10. Guyatt GH (1993). Measurement of health-related quality of life in heart failure. *J Am Coll Cardiol* 22: 185A–191A.
11. Wilson IB, Cleary PD (1995). Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *J Am Med Assoc* 273: 59–65.
12. Ferrans CE (1996). Development of a conceptual model of quality of life. *Sch Inq Nurs Pract* 10: 293–304.
13. Vallerand AH (2003). The use of long-acting opioids in chronic pain management. *Nurs Clin North Am* 38: 435–45.
14. Ferrans CE, Zerwic JJ, Wilbur JE, Larson JL (2005). Conceptual model of health-related quality of life. *J Nurs Scholarship* 37: 336–42.
15. Rector TS (2005). A conceptual model of quality of life in relation to heart failure. *J Card Fail* 11: 173–6.
16. Cella DF (1992). Quality of life: the concept. *J Palliat Care* 8: 8–13.
17. Spilker B (1996). Introduction. In: *Quality of Life and Pharmacoeconomics in Clinical Trials* (ed. B Spilker), pp. 1–10. Philadelphia: Lippincott-Raven.
18. Friedman M (1997). Older adults' symptoms and their duration before hospitalization for heart failure. *Heart Lung* 26: 169–76.
19. Todero CM, LaFramboise LM, Zimmerman LM (2002). Symptom status and quality-of-life outcomes of home-based disease management program for heart failure patients. *Outcomes Manag* 6: 161–8.
20. Nordgren L, Sorensen S (2003). Symptoms experienced in the last six months of life in patients with end-stage heart failure. *Eur J Cardiovasc Nurs* 2: 213–17.
21. Horowitz CR, Rein SB, Leventhal H (2004). A story of maladies, misconceptions and mishaps: effective management of heart failure. *Soc Sci Med* 58: 631–43.
22. Friedman MM, Griffin JA (2001). Relationship of physical symptoms and physical functioning to depression in patients with heart failure. *Heart Lung* 30: 98–104.
23. Gorkin L, Norvell NK, Rosen RC *et al.* (1993). Assessment of quality of life as observed from the baseline data of the Studies of Left Ventricular Dysfunction (SOLVD) trial quality-of-life substudy. *Am J Cardiol* 71: 1069–73.
24. Friedman M, King K (1994). The relationship of emotional and tangible support to psychological well-being among older women with heart failure. *Res Nurs Health* 17: 433–40.
25. Gott M, Barnes S, Parker C *et al.* (2006). Predictors of the quality of life of older people with heart failure recruited from primary care. *Age Ageing* 35: 172–7.
26. De Jong M, Moser DK, Chung ML (2005). Predictors of health status for heart failure patients. *Prog Cardiovasc Nurs* 20: 155–62.
27. Haworth JE, Moniz-Cook E, Clark AL, Wang M, Waddington R, Cleland JG (2005). Prevalence and predictors of anxiety and depression in a sample of chronic heart failure patients with left ventricular systolic dysfunction. *Eur J Heart Fail* 7: 803–8.
28. Majani G, Pierobon A, Giardini A *et al.* (1999). Relationship between psychological profile and cardiological variables in chronic heart failure. The role of patient subjectivity. *Eur Heart J* 20: 1579–86.
29. Moser DK, Zambroski CH, Lennie TA *et al.* (2004). Aging with a broken heart: The effect of heart disease on psychological distress in the elderly [abstract]. *Circulation* 110(Suppl.): 416.
30. Vaccarino V, Kasl SV, Abramson J, Krumholz HM (2001). Depressive symptoms and risk of functional decline and death in patients with heart failure. *J Am Coll Cardiol* 38: 199–205.
31. Thomas SA, Friedmann E, Khatta M, Cook LK, Lann AL (2003). Depression in patients with heart failure: physiologic effects, incidence, and relation to mortality. *AACN Clin Issues* 14: 3–12.
32. Murberg T, Aarsland T, Svebak S (1998). Functional status and depression among men and women with congestive heart failure. *Int J Psychiat Med* 28: 273–91.
33. Carels RA (2004). The association between disease severity, functional status, depression and daily quality of life in congestive heart failure patients. *Qual Life Res* 13: 63–72.
34. Riedinger MS, Dracup KA, Brecht ML, Padilla G, Sarna L, Ganz PA (2001). Quality of life in patients with heart failure: do gender differences exist? *Heart Lung* 30: 105–16.
35. Riegel B, Moser DK, Carlson B *et al.* (2003). Gender differences in quality of life are minimal in patients with heart failure. *J Card Fail* 9: 42–8.
36. Evangelista LS, Kagawa-Singer M, Dracup K (2001). Gender differences in health perceptions and meaning in persons living with heart failure. *Heart Lung* 30: 167–76.
37. Hou N, Chui MA, Eckert GJ, Oldridge NB, Murray MD, Bennett SJ (2004). Relationship of age and sex to health-related quality of life in patients with heart failure. *Am J Crit Care* 13: 153–61.
38. Carels RA, Musher-Eizenman D, Cacciapaglia H, Perez-Benitez CI, Christie S, O'Brien W (2004). Psychosocial functioning and physical symptoms in heart failure patients: a within-individual approach. *J Psychosom Res* 56: 95–101.
39. Bennett SJ, Perkins SM, Lane KA, Deer M, Brater DC, Murray MD (2001). Social support and health-related quality of life in chronic heart failure patients. *Qual Life Res* 10: 671–82.
40. Luttik ML, Jaarsma T, Moser D, Sanderman R, van Veldhuisen DJ (2005). The importance and impact of social support on outcomes in patients with heart failure: an overview of the literature. *J Cardiovasc Nurs* 20: 162–9.
41. Riegel B, Carlson B, Glaser D, Romero T (2003). Changes over 6-months in health-related quality of life in a matched sample of Hispanics and non-Hispanics with heart failure. *Qual Life Res* 12: 689–98.
42. Blair AS, Lloyd-Williams F, Mair FS (2002). What do we know about socioeconomic status and congestive heart failure? A review of the literature. *J Fam Pract* 51: 169.
43. Green CP, Porter CB, Bresnahan DR, Spertus JA (2000). Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. *J Am Coll Cardiol* 35: 1245–55.
44. Rector T, Kubo S, Cohn J (1987). Patient's self-assessment of their congestive heart failure. Part 2: Content, reliability and validity of a new measure, The Minnesota Living with Heart Failure Questionnaire. *Heart Fail* 1: 198–209.
45. Bennett SJ, Oldridge NB, Eckert GJ *et al.* (2003). Comparison of quality of life measures in heart failure. *Nurs Res* 52: 207–16.
46. Nasution SA (2006). The use of ACE inhibitor in cardiovascular disease. *Acta Med Indones* 38: 60–4.
47. Jenkinson C, Jenkinson D, Shepperd S, Layte R, Petersen S (1997). Evaluation of treatment for congestive heart failure in patients aged 60 years and older using generic measures of health status (SF-36 and COOP charts). *Age Ageing* 26: 7–13.
48. Wolfel EE (1998). Effects of ACE inhibitor therapy on quality of life in patients with heart failure. *Pharmacotherapy* 18: 1323–34.
49. Reddy P, Dunn AB (2000). The effect of beta-blockers on health-related quality of life in patients with heart failure. *Pharmacotherapy* 20: 679–89.

50. Phillips CO, Wright SM, Kern DE, Singa RM, Shepperd S, Rubin HR (2004). Comprehensive discharge planning with postdischarge support for older patients with congestive heart failure: a meta-analysis. *J Am Med Assoc* 291: 1358–67.
51. McAlister FA, Stewart S, Ferrua S, McMurray JJJV (2004). Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials. *J Am Coll Cardiol* 44: 810–19.
52. Gwady-Sridhar FH, Flintoft V, Lee DS, Lee H, Guyatt GH (2004). A systematic review and meta-analysis of studies comparing readmission rates and mortality rates in patients with heart failure. *Arch Intern Med* 164: 2315–20.
53. Riegel B, Carlson B, Glaser D, Hoagland P (2000). Which patients with heart failure respond best to multidisciplinary disease management? *J Card Fail* 6: 290–9.
54. Riegel B, Carlson B, Kopp Z, LePetri B, Glaser D, Unger A (2002). Effect of a standardized nurse case-management telephone intervention on resource use in patients with chronic heart failure. [see comment]. *Arch Intern Med* 162: 705–12.
55. Riegel B, Carlson B, Glaser D, Romero T (2006). Randomized controlled trial of telephone case management in Hispanics of Mexican origin with heart failure. *J Card Fail* 12: 211–19.
56. Spertus J, Peterson E, Conard MW *et al.* (2005). Monitoring clinical changes in patients with heart failure: a comparison of methods. *Am Heart J* 150: 707–15.
57. World Health Organization, Division of Mental Health (1993). *WHO-QOL study protocol: the development of the world health quality of life assessment instruments*. Geneva: World Health Organization.
58. Ferrans CE, Powers MJ (1985). Quality of life index: development and psychometric properties. *ANS Adv Nurs Sci* 8: 15–24.
59. Osoba D (1994). Lessons learned from measuring health-related quality of life in oncology. *J Clin Oncol* 12: 608–16.

Chapter 9

Dyspnoea

Patricia M. Davidson, Phillip J. Newton, and Peter S. Macdonald

Objectives for this chapter

Supportive care in heart failure (HF) management is the multidisciplinary holistic care of patients and their families from the time of diagnosis, during treatment aimed at prolonging life, through to the end of life when palliative care is provided.¹ The management of dyspnoea is a key consideration in supportive care of HF. This chapter will describe the physiological basis of dyspnoea, present a conceptual model for perceiving and managing dyspnoea, outline pharmacological and non-pharmacological strategies, and summarize key considerations for clinicians, patients, and their families to manage this debilitating symptom. In spite of the frequency and severity of dyspnoea, sparse information exists on symptom management in a supportive model of HF care. However, from experience obtained in other clinical conditions, interventions such as self-management techniques and the prescribing of anxiolytic and opiate medications can be expected to reduce the symptomatic burden of dyspnoea in addition to HF-specific treatments.^{2,3} A supportive approach to care in HF requires a change as the disease progresses from a focus on one of prolongation of life to symptom management and promotion of quality of life.¹ A useful but limited armamentarium is available for the clinician to treat dyspnoea in HF. In spite of the burden and prevalence of dyspnoea, the pathophysiological processes remain poorly understood, not just in HF but across a range of conditions. As the reader works through this chapter it is important to consider recommendations within the paradigm of supportive care. Supportive care involves recognizing and caring for the side-effects of active therapies, patients' co-morbidities, psychological, social, and spiritual concerns, as well as addressing family needs.⁴

In this chapter we aim to: (1) describe the physiological basis of dyspnoea; (2) discuss a conceptual model for the patient's perception and management of dyspnoea; (3) outline useful pharmacological and non-pharmacological strategies; and (4) summarize key considerations for patients, their families, and clinicians to manage this complex symptom. Dyspnoea (breathlessness) is defined as the sensation and/or perception of shortness of breath. Breathlessness impacts upon the individual's quality of life by reducing the ability of the person to sustain their normal activities. This limitation can range from dyspnoea on exertion [New York Heart Association (NYHA) Class II], which is mildly troublesome, through to being breathless at rest (NYHA Class IV), which is severely debilitating.