



# **Chapter 4:** **QUALITY OF LIFE**

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# Increase Reimbursement for Services Related to Quality of Life at Time of Diagnosis and Throughout the Cancer Continuum

## Rationale

Quality of life is difficult to define. It is a moving target that changes at different points in a person's life. Many of the strategies in this chapter represent "health-related" quality of life but are not limited to that. Quality of life indicators in individuals diagnosed with cancer can vary, however, for purposes of defining the parameters in this report they might include: pain, fatigue, depression/psycho-social and nutrition. Impediments to effective symptom management to enhance quality of life can arise from different sources and interactions among providers, patients and their families and the health care system.

Cancer survivors are dealing with many different physical and emotional needs, many of which are not covered by insurance. While Medicare, private health insurance, Medicaid, and Health Insurance Risk Sharing Plan (HIRSP) do cover pain management and palliative care for patients who meet eligibility criteria, other necessary non-medical services are not covered. Research has shown that the more holistically patients are treated, the better their treatment outcomes. Wisconsin needs to assess the current state of quality of life services that are reimbursed to begin to increase coverage for all survivors.

## Disparate Burden

As mentioned in Chapter 3: Treatment, there is a disparate burden of access to healthcare in Wisconsin. According to *The Health of Racial and Ethnic Populations in Wisconsin, 1996–2000*, the following groups in Wisconsin were uninsured for an entire year: Hispanic/Latinos (13%), African Americans (10%), Native Americans (7%), Asian-Americans (7%) and whites (4%).<sup>7</sup> Lack of insurance not only makes it difficult to obtain treatment, but also to obtain services related to quality of life. Besides having health insurance, lack of transportation, language barriers and education levels can all be culturally linked barriers that contribute to the disparate burden of accessing quality of life care. Having a healthcare system that is difficult to navigate only widens the burden.

## What Can Be Done?

- Educate employers and consumers regarding the importance of including quality of life (QOL) services for cancer patients and their families in benefit packages.
- Enact public policy to ensure comprehensive coverage of quality of life services.
- Establish a gold standard reimbursement model for payers to include QOL services for cancer patients and their caregivers.

## Targets for Change

SURVIVORSHIP	
Increase percent of survivors who are living five years or longer after diagnosis	
WI Rate 2003	Healthy People 2010 Target
62% survivor rate	70% survivor rate
16,000 people	18,050 people

Sources:

American Cancer Society. Wisconsin Cancer Facts and Figures 2003-2004. Pewaukee, WI. 2003.

U.S. Department of Health and Human Services. Healthy People 2010. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

CANCER MORTALITY		
Reduce overall cancer death rate		
WI Mortality Rate (1996–2000)	Healthy People 2010 Target	Percent Decrease Needed to Achieve Healthy People 2010 Goal in WI
195.7%	159.9%	18%

Sources:

American Cancer Society. Wisconsin Cancer Facts and Figures 2003-2004. Pewaukee, WI. 2003.

U.S. Department of Health and Human Services. Healthy People 2010. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: U.S. Government Printing Office, November 2000.

1. Rates are averaged per 100,000 population and age-adjusted to the 2000 U.S. standard population.



<b>STRATEGY A: Educate employers and consumers regarding the importance of including quality of life (QOL) services for cancer patients and their families in benefit packages.</b>	
<b>Action Plan</b>	<b>Recommended Implementation Steps</b>
Develop an education plan to help employers and consumers understand the importance of including quality of life services in benefit packages.	Develop and implement a survey to identify gaps in knowledge regarding quality of life – both at the employer and consumer/employee level.
	Use survey results to develop an education plan to help employers and consumers understand the importance of including quality of life services in benefit packages.
	Present this education plan to employers and consumers.

<b>STRATEGY B: Enact public policy to ensure comprehensive coverage of quality of life services.</b>	
<b>Action Plan</b>	<b>Recommended Implementation Steps</b>
Assess problem of QOL services reimbursement among cancer patients.	Survey cancer patients, caregivers and providers to identify gaps in reimbursement for QOL services.
	Analyze survey results to identify uninsured and medically underserved and identify their unique barriers to QOL services.
Work to gain support among legislators for reimbursement of QOL services.	Present survey results and personal cancer survivor stories to legislators to gain their interest in QOL reimbursement policy.
	Survey legislators to determine interest in QOL or cancer issues and ask for their support in reimbursement issues.
Build a grassroots campaign to support public policy for reimbursement of QOL services.	Identify a coalition of supporting organizations that can offer grassroots support.
	Research other QOL policy initiatives and legislative mandates that have been enacted in other states.

<b>STRATEGY C: Establish a gold standard reimbursement model for payers to include QOL services for cancer patients and their caregivers.</b>	
<b>Action Plan</b>	<b>Recommended Implementation Steps</b>
Determine a gold standard reimbursement model for Wisconsin.	Survey cancer patients and cancer survivors to identify QOL services that are commonly not covered by third party payers, Medicare and Medicaid.
	Interview providers and QOL experts to determine what the gold standard should include.
	Research reimbursement models for QOL services in other states.
	Draft gold standard reimbursement model.
Implement a gold standard reimbursement model among payers in Wisconsin.	Develop a communications plan to alert payers/health insurers about gold standard.
	Develop a system for rewarding and recognizing payers/insurers who are following the gold standard.

# Provide Education that will Enhance the Understanding of the Importance of Quality of Life in the Treatment Continuum

## Rationale

Over 60% of those diagnosed with cancer today are expected to be five-year cancer survivors.<sup>20</sup> The number of cancer survivors is expected to increase as the population ages and cancer detection and treatment improve. Cancer survivors are faced with difficult medical and life decisions at each stage of living with the disease. From the time of diagnosis, the quality of life for every cancer patient and survivor is affected in some way. Cancer patients and their families face many issues such as cancer pain management, psychological support, access to quality care, financial and health insurance advice, sexual functioning, nutrition counseling, post-treatment concerns and end of life concerns.<sup>20</sup> Because many contributing variables affect one's enjoyment of life, a personal assessment of well-being is more complex and subjective than other quantitative measurements.

## Disparate Burden

The physical and psychosocial needs of medically underserved cancer survivors and their families must be considered within the context of quality of life. Also quality of life is affected by many socio-cultural variables that affect cancer survivorship. The nature and effectiveness of existing post-treatment medical and support services designed for cancer patients from underserved communities need to be researched and strengthened.

## What Can Be Done?

- Educate cancer care providers about the importance of symptom management as it impacts quality of life.
- Educate patients and caregivers about the importance of defining and communicating quality of life needs and issues with their healthcare provider.

## Targets for Change

QUALITY OF LIFE	
Cancer Patient Bill of Rights	
2004	2010 Target
No cancer patient bill of rights	Wisconsin specific Patient Bill of Rights

<b>STRATEGY A: Educate cancer care providers about the importance of symptom management as it impacts quality of life.</b>	
Action Plan	Recommended Implementation Steps
Design professional education outreach to promote symptom management in individuals living with cancer.	Assemble a panel of experts and define "appropriate symptom management in cancer care."
	Develop a Patient Bill of Rights for expectations of cancer care.
	Develop and promote minimum competencies for each cancer care profession regarding their role in cancer pain and symptom assessment and management.
Develop and promote patient advocacy systems for people living with cancer.	Identify American College of Surgeons (ACoS) Commission on Cancer (CoC) facilities in Wisconsin with action plans addressing symptom management.
	Recruit individuals to function as "patient advocates" for appropriate pain and symptom management in all of the ACoS CoC facilities and/or community hospitals.
	Provide training about management of pain and other adverse symptoms of cancer treatment to the patient advocates.

<b>STRATEGY B: Educate patients and caregivers about the importance of defining and communicating quality of life needs and issues with their healthcare providers.</b>	
Action Plan	Recommended Implementation Steps
Develop multi-cultural campaign to demonstrate the importance of quality cancer care in meeting successful treatment outcomes.	Identify existing multi-cultural materials that demonstrate how to communicate effectively with health professionals about quality of life needs for individuals experiencing cancer.
Sponsor Annual Cancer Survivors Day.	Assess current statewide activities around the Annual Cancer Survivors Day to focus on the broad spectrum of quality of life issues during and after treatment.

# Assemble Data on Quality of Life to Establish Best Practices in Measuring Optimal Treatment Outcomes

## Rationale

Quality of life is a very important issue for cancer patients and their loved ones. It is receiving increasing attention around the country by organizations that represent and/or work with cancer patients and by other statewide comprehensive cancer planning groups.<sup>21</sup> There is little hard data in terms of defining where Wisconsin stands in meeting the quality of life needs of its citizens living with cancer.<sup>22</sup> There are many ways to define quality of life and no consistent, agreed-upon way to measure it.<sup>23</sup> There is a nationally developed standard for collecting baseline information about quality of survival, but it is not being used at a population-based collection level. In addition, there currently is no support from state, national or federal organizations, nor are there federal mandates for collecting the data. Also, there has been little funding at the state or federal level to support surveillance programs that monitor these issues. As increasing attention is given to quality of life issues, the data collected to support work in this area needs to increase as well.

## Disparate Burden

Data collection for racial and ethnic variables have known limitations, including underreporting, misclassification, and incomplete data items.<sup>24</sup> We don't want these same issues to occur with measuring quality of life and optimal treatment outcomes. As we move forward in collecting quality of life data, we must build in measurements for racial and ethnic variables.

## What Can Be Done?

- Establish and implement a statewide repository of quality of life outcomes data.
- Establish evidence-based quality of life interventions.

## Targets for Change

QUALITY OF LIFE	
Data and Interventions	
2004	2010 Target
No Statewide repository of QOL outcomes data or evidence-based QOL interventions.	Create statewide repository and evidence-based interventions.

<b>STRATEGY A: Establish and implement a statewide repository of quality of life outcomes data.</b>	
<b>Action Plan</b>	<b>Recommended Implementation Steps</b>
Identify potential elements for quality of life data repository.	Develop links and partnerships with state and national registries for collection and reporting of quality of life outcomes data.
	Review capabilities for data capture and use with existing registries and studies.
	Determine whether there are privacy or legal protections that may impede process (e.g., HIPAA).
Establish a uniform assessment tool to collect quality of life outcome data.	Search for evidence-based QOL interventions that include quality of life outcomes assessment.
	Form expert review committee to recommend essential quality of life indicators, variables, and measures.
	Consult with key persons in quality of life assessment on length and format of measures.

<b>STRATEGY B: Establish evidence-based quality of life interventions.</b>	
<b>Action Plan</b>	<b>Recommended Implementation Steps</b>
Convene a taskforce to review and recommend evidence-based quality of life interventions to implement in Wisconsin.	Collect and evaluate quality of life education and support materials available.
	Form an expert review subcommittee to recommend targeted evidence-based quality of life protocol.
	Implement evidence-based programs proven to be effective.

### References

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