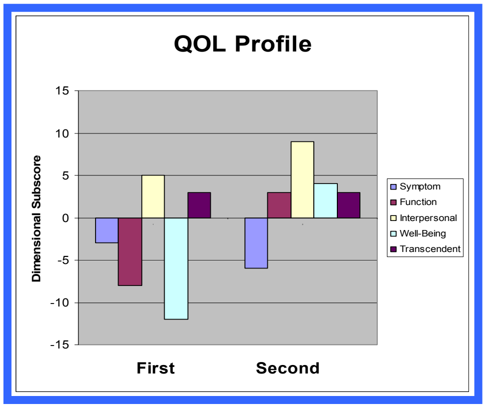

The Missoula-VITAS Quality of Life Index (MVQOLI)©

AN OUTCOME MEASURE FOR PALLIATIVE CARE

Guide to Using the MVQOLI

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> *Quality of life (QOL) in the context of advanced, progressive, incurable illness, is defined as the subjective experience of an individual living with the interpersonal, psychological and existential or spiritual challenges that accompany the process of physical and functional decline and the knowledge of impending demise. A person's QOL can range from suffering, associated with physical distress and/or a sense of impending disintegration, to the experience of wellness and personal growth arising from the completion of developmental work and the mastery of developmental landmarks.*
>
> *Byock and Merriman, Pall. Med.,* ***12****:231-244, 1998.*

This guide is designed to assist you in implementing the Missoula-VITAS Quality of Life Index. It will be most useful for implementation on a small scale or in a pilot study.

The materials are excerpted and adapted from training materials originally created by VITAS Healthcare Corporation and The Hospice Institute of the Florida Suncoast.

For full implementation throughout your organization, we strongly recommend that you attend the 1.5 day training offered at The Hospice Institute of the Florida Suncoast. For information on the training course, contact Susan Bruno at 727-773-2531 or susanbruno@thehospice.org.

Here is a sample of topics covered in the training program:

- History and philosophy of the MVQOLI and its use in patient care
- Patient/Family Value-directed Care
- The Patient Quality of Life Profile
- Implementation of the MVQOLI in your organization
- Using the MVQOLI Excel scoring tool

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I. Background on the MVQOLI

The Missoula-VITAS Quality of Life Index (MVQOLI) is an assessment instrument that gathers patient-reported information about quality of life during advanced illness. Maintaining optimal quality of life is a core goal of palliative and hospice care, and information gathered via the MVQOLI assists health care professionals in identifying and addressing patient concerns that affect quality of life. The MVQOLI has been used in many different healthcare settings including hospice, hospital, home health, long-term care (including assisted living), outpatient palliative care, disease management and pre-hospice programs.

The MVQOLI was developed in 1995 by Ira Byock, MD, Melanie Merriman, PhD, and Barry Kinzbrunner, MD (Chief Medical Officer at VITAS Healthcare Corporation), and revised in 2004. More information on the development, reliability, validity, and use of the MVQOLI in practice can be found in the following publications:

> Byock IR, Merriman MP. Measuring quality of life for patients with terminal illness: the Missoula-VITAS quality of life index. *J. Pal. Med.* 1998; 12:231-244.
>
> Hill N. Use of quality of life scores in care planning in a hospice setting: a comparative study. International Journal of Palliative Nursing 8[11], 540-547. 2002. New Zealand.
>
> Hill N. Use of quality of life scores in care planning in a hospice setting: the theme of revelation. *International Journal of Palliative Nursing* 2002; 8(12):591-593.
>
> Schwartz CE, Merriman M, Reed G, Ma Y, and Byock I. Evaluation of the Missoula-VITAS Quality of Life Index – Revised: Research tool or clinical tool? *Journal of Palliative Medicine* 2005: 8 (1): 121-135.

Design and structure of the MVQOLI:

The framework of the Missoula-VITAS Quality of Life Index is based on Ira Byock's work regarding growth and development at the end of life and the concepts of landmarks and tasks of life closure. (*Byock, IR: The nature of suffering and the nature of opportunity at the end of life. Clin. Ger. Med., 12, 237-252, 1996.)*

The MVQOLI asks patients about 5 dimensions or domains of quality of life: symptoms; function; interpersonal; well-being; and transcendence. (See definitions below.) The instrument is specifically designed to assess the patients *personal experience* in each of these dimensions, hence the MVQOLI items are constructed with highly subjective language and no scores appear on the version of the tool seen by patients. The tool seeks to describe the qualitative and subjective experience of quality of life in a way that can be quickly interpreted by professional caregivers.

Within each dimension, three kinds of information are gathered from respondents in order to illuminate their overall experience:

- **Assessment** – subjective measurement of actual status or circumstance (What it is.) *Example: I feel sick all the time.*
- **Satisfaction** – degree of acceptance or mastery of actual circumstance (How much does it bug you?) *Example: I am satisfied with current control of my symptoms.*
- **Importance** – degree to which a given dimension has an impact on overall quality of life (How much does it matter?) *Example: Despite physical discomfort, I can still enjoy my days.*

Each dimension is defined by the patient's perception and/or experience – not the "judgment" of caregivers (family or professional.) The definitions for the dimensions and examples of items for each response category are shown below.

Symptoms - experience of the physical discomfort associated with progressive illness; perceived level of physical distress.

(A) 1. I feel sick all the time.

(S) 2. I am satisfied with current control of my symptoms.

(I) 3. Physical discomfort overshadows any opportunity for enjoyment.

Function - perceived ability to perform accustomed functions and activities of daily living, experienced in relation to expectations.

(A) 4. I am no longer able to do many of the things I like to do.

(S) 5. I accept the fact that I cannot do many of the things that I used to do.

(I) 6. My contentment with life depends upon being active and being independent in my personal care.

Interpersonal - degree of investment in personal relationships and the perceived quality of one's relations with family and friends.

(A) 7. I have recently been able to say important things to the people close to me.

(S) 8. At present, I spend as much time as I want with family and friends.

(I) 9. It is important to me to have close personal relationships.

Well-Being - self-assessment of an internal condition; subjective sense of emotional "wellness" or "dis-ease"; contentment or lack of contentment with self.

(A) 10. My affairs are not in order; I am worried that many things are unresolved.

(S) 11. I am more satisfied with myself as a person now than I was before my illness.

(I) 12. It is important to me to be at peace with myself.

Transcendent - experienced degree of connection with an enduring construct; degree of experienced meaning and purpose in life.

(A) 13. I have a better sense of meaning in my life now than I have had in the past.

(S) 14. Life has lost all value for me; every day is a burden.

(I)15. It is important to me to feel that my life has meaning.

There are two versions of the MVQOLI – 15 item and 25 item. The instrument was initially designed with 25 items. Clinicians reported that the tool was too long for some patients to complete. Using data from the original study of reliability and validity, a 15-item version was constructed that has a correlation coefficient of .93 with the 25-item version, indicating that little information is lost when only 15 items are used. The newest versions of the tool included with this guide have been revised using simpler language and item formats to make it easier to use for both patients and staff.

II. MVQOLI Administration

Through the reported experience of clinicians who have used the MVQOLI in various settings and through our own research, we have developed the following recommendations concerning use of the MVQOLI. The five primary considerations are:

- Which patients will be asked to complete the instrument?
- When should the MVQOLI be administered?
- Who should administer the MVQOLI?
- How to introduce and administer the instrument.
- Tracking MQVOLI use by all patients

We suggest that MQVOLI users keep the following principles in mind when determining how they will use the instrument:

- The MVQOLI is designed to assess the patient's experience so they need to interpret the questions for themselves. When reading the items to a patient, try not to get into a discussion about the meaning of the item.

- The MVQOLI is meant to help clinicians to understand patient needs and concerns and then to *help the patient achieve better quality of life.* Getting the "data" is never as important as helping the patient so if administration of the tool opens a therapeutic opportunity – take it.

- If patients become upset while completing the tool, this may indicate an area of concern. Clinicians report to us that this is often an excellent therapeutic opportunity. However, patients also have the right to refuse the MVQOLI and stop if they find it too upsetting. Many choose to continue even when upset and then are eager to discuss their feelings.

Patient Eligibility Criteria: Which patients should complete the MVQOLI?

1. The MVQOLI has been used with palliative care and hospice patients in a variety of settings including hospice, hospital, home health, long-term care (including assisted living), outpatient palliative care, and pre-hospice programs. It is appropriate for any patient population facing advanced, chronic, progressive illness.

2. The MVQOLI was developed in English and had been rigorously translated and back-translated into Spanish. We recommend use only with patients who can communicate in these languages. They do not have to be able to read or mark the instrument themselves as long as they can understand and communicate their responses.
   It is critical that the concepts, and not just the words, of the MVQOLI be correctly interpreted by respondents. Translation into other languages " on the spot" by caregivers is discouraged. The authors are, however, interested in collaborating on efforts to carefully create versions in other languages.

3. The MVQOLI has been validated only with patients 18 years or older, however, it has been used in practice with patients as young as 12.

4. Patients with dementia or cognitive impairments that cast doubt on the reliability of their responses are best excluded.

5. Patients in extreme denial or whose emotional state is so fragile that clinicians feel the MVQOLI might exacerbate their symptoms should be excluded.
   ***However,** in both research and reported experience, we find that clinicians tend to be **too conservative** in their use of the MVQOLI. Patients are much more receptive to the MVQOLI than clinicians think they will be.*

When to administer the first MVQOLI

In routine practice, the first MVQOLI should be administered as soon after admission as is practical for staff and the patient. The sooner the information is available to the clinical team, the sooner they can use it for care planning. MVQOLI information enhances the creation of care plans that specifically address patient needs and concerns. In addition, since the MVQOLI is meant to be administered several times over a patient's course of care, the first administration serves as a baseline measure and is most accurate for that use when administered close to admission. (Note that in hospice settings, clinicians report that the admission visit is often very stressful and requires considerable paperwork. For these reasons, it may not be a good time to administer the MVQOLI.)

In fact, the MVQOLI can be administered at any time that the team feels the information will help them to care for the patient. In our own studies, the first MVQOLI was sometimes administered to patients who had been on service for weeks or months. Interestingly, clinical staff were often surprised that the information gathered offered new insights into patients they thought they knew well.

Who should administer the MVQOLI?

Any member of the clinical team **who has been trained** to administer the MVQOLI could do so. In practice, clinicians report that home health aides often report being uncomfortable dealing with the issues in the MVQOLI. We also feel that volunteers, unless they are healthcare professionals, could not bring necessary clinical expertise to administration of the MVQOLI.

In determining who will administer the tool, consider the fact that most patients will want to discuss their answers. Recent studies on implementation have suggested that psychosocial staff are most interested in using the MVQOLI and may have more time to do so than nursing staff. In addition, they maybe uniquely qualified to deal with some of the issues that patients want to discuss.

In order to make administration manageable for the clinical staff, it is best to do it as part of a regular visit. In some cases, the MVQOLI may serve as a reason for a visit by psychosocial staff even for patients who have declined to see a social worker or chaplain.

How to introduce and administer the MVQOLI

Learning to administer the MVQOLI, like any other clinical skill, requires training and practice. We strongly recommend that you include role playing practice in your training session.

When introduced and explained carefully, the MVQOLI is acceptable to and even welcomed by patients. As for any other clinical intervention, patients should be informed as to the purpose and given an opportunity to ask questions. Ultimately it is their decision whether to complete the assessment.

We have found the following checklist of information to cover useful in training and practicing administration of the MVQOLI.

Administering the MVQOLI
Initial Survey Check List

____ I want to ask you to answer a questionnaire about your quality of life. Our clinical team likes to use this questionnaire to help us understand your unique situation so that we can provide the type of care that will help you the most.

____ Completing the questionnaire is optional, but I hope you will do it in order to help us to help you.

____ It will take about 10-15 minutes, but you can take as long as you need.

____ There are no “wrong” answers. The questionnaire is about your feelings about things.

____ {Show the MVQOLI to the patient.] Every item is a statement and you are asked to mark a circle to show whether you agree strongly, agree, disagree, disagree strongly, or feel neutral about the statement.

____ If you start to fill it out and change your mind, you can just stop. If you decide not to complete the questionnaire, we will still do everything we can to take care of you the best way we know how.

____ We will ask you to fill this out again every few weeks to help us keep up with what is important to you.

____ Would you like to fill it out by yourself, or would you like for me to read the questions to you? [If the patient is reluctant to complete the MVQOLI, encourage gently emphasizing how it will help the team to serve the patient well. If they still refuse, thank them and reiterate that it is their choice.]

Ideally, the patient will agree to complete the instrument on their own (which is the preferred method), and the clinician will give them some time to do so while completing paperwork or making phone calls in another room. If they agree to complete it on their own and the clinician cannot wait, arrange for the completed MVQOLI to be picked up by the next team member to visit. In many cases, the patient will ask to have the questions read and the clinician will administer the MVQOLI as an “interview”.

If the patient completes the questionnaire on their own, use this checklist for collecting the completed MVQOLI.

MVQOLI Collection Check List

____ If the survey has not been completed, ask the patient if they want more time or prefer not to do it.

____ Check to see if the date is filled in. If the date is not filled in, ask the patient when it was completed and fill in the date. If the patient is not sure of the date, use today’s date.

____ Check to make sure all the questions are answered and that there is only one answer per question. If an answer is blank please ask the patient to complete the unanswered question. If they answered a question more than once, ask them which answer they would like to have recorded.

____ If the survey is completed, thank the patient for completing it and ask if they would like to see the results after it is recorded. If so, let patient know a team member will return with it and make sure to mention this at the care planning meeting when the patient profile is discussed.

____ Return the survey to the office as soon as possible for data entry.

Tracking use of the MVQOLI

The agency should develop a system for tracking the use of the MVQOLI with every patient – even patients who are ineligible or refuse. The Date Due Tool provided includes tables for tracking the use of the MVQOLI with each patient admitted. (Links to the Date Due Excel file and instructions are provided in Appendices 9-10 at the end of this guide.) However, the agency will have to develop systems for staff to report whether the MVQOLI was or was not completed and why.

III. MVQOLI Scoring – Turning patient answers into the *Quality of Life Profile*

The MVQOLI is an assessment instrument and it is critical that the information gathered be shared with the team as quickly as possible after the patient has completed the tool.

The MVQOLI can be scored using an **EXCEL program or manually**. Detailed instructions for each method are in Appendices 5-8 at the end of this manual.

The MVQOLI scoring protocol is designed to turn the qualitative subjective experience of the patient into quantitative information that can be easily interpreted by the care team. The unique scoring system has the advantage of revealing how much each domain affects QOL. For example, efforts to make a patient comfortable may contribute little to QOL if that domain is not important to them. In addition, small changes in any domain may affect QOL a lot if that domain is very important to the patient

The MVQOLI items are scored as follows:

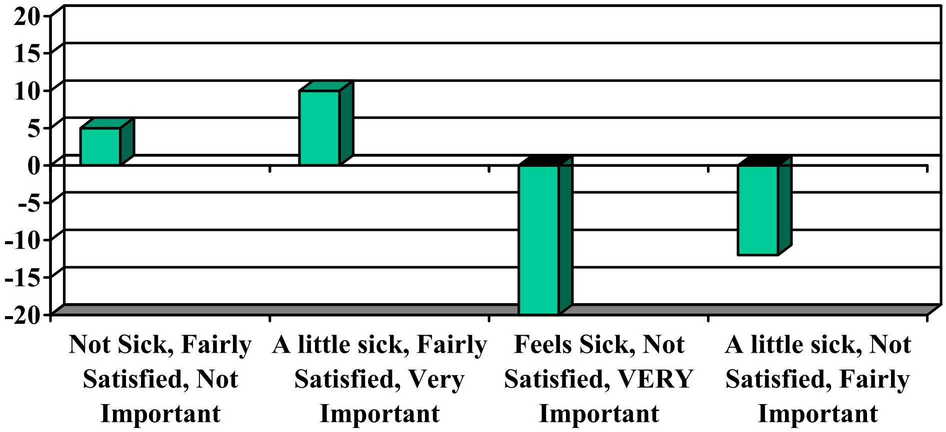
Assessment	-2 to +2
Satisfaction	-4 to +4
Importance	1 to 5
(Assessment + Satisfaction) X Importance = QOL in each dimension	

Note that the assessment and satisfaction scores can range from -6 to +6 and indicate whether the patient assess his/her situation positively or negatively. When multiplied by the importance factor, the overall dimension score is magnified by how important that domain is.

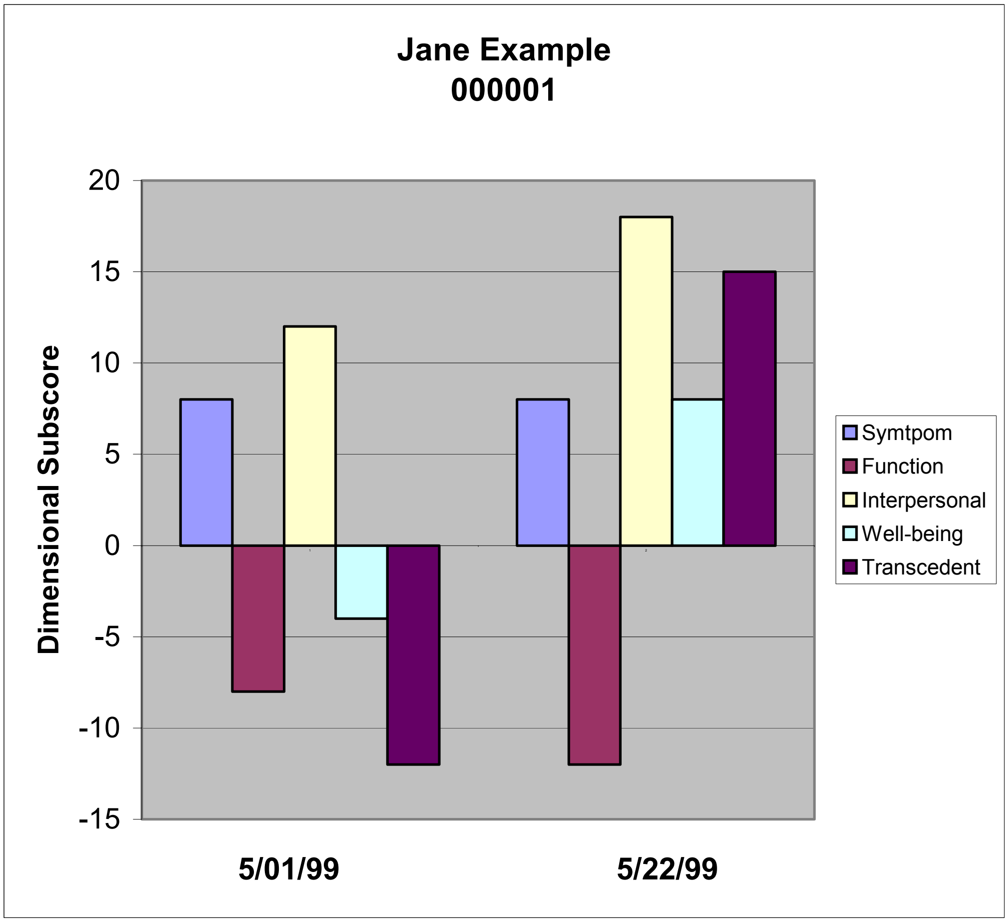
The final score in each dimension reflects the overall impact of that domain on quality of life.

- **Negative dimensions are reducing quality of life;**
- **Positive dimensions are increasing quality of life; and**
- **The size of each dimension reflects the amount of impact.**

The results are easy to interpret when viewed on a bar graph. Different answers affect the size of the bars as shown here:



The results of the entire MVQOLI are displayed in the Quality of Life Profile.



IV. Using the MVQOLI Quality of Life Profile for Care Planning

It is important to train the clinical team in using the MVQOLI quality of life profile for care planning. **We feel strongly that administration of the instrument without follow up in terms of clinical care is irresponsible.** Patients reveal feelings and concerns that should be understood and addressed by the clinical team.

The quality of life profile should be generated and distributed to the team as soon after completion of the MVQOLI as possible. Like all clinical skills, use of the MVQOLI information in care planning and care delivery will require training and practice.

Interpreting the QOL Profile

- Results are presented as a bar graph – each dimensions of QOL is a bar
- The size of the bar reflects the amount that each dimension is affecting QOL
- Positive dimensions are adding to QOL (+ = add, increase)
- Negative dimensions are subtracting quality of life (- = decrease, detract)

Using the QOL profile as a tool in care planning

The MVQOLI information is only one piece of the picture and should be integrated with other information gathered in other ways. It does not replace the clinical experience and judgment of the team.

Consider how well the QOL profile fits with all the other information you have about the patient.

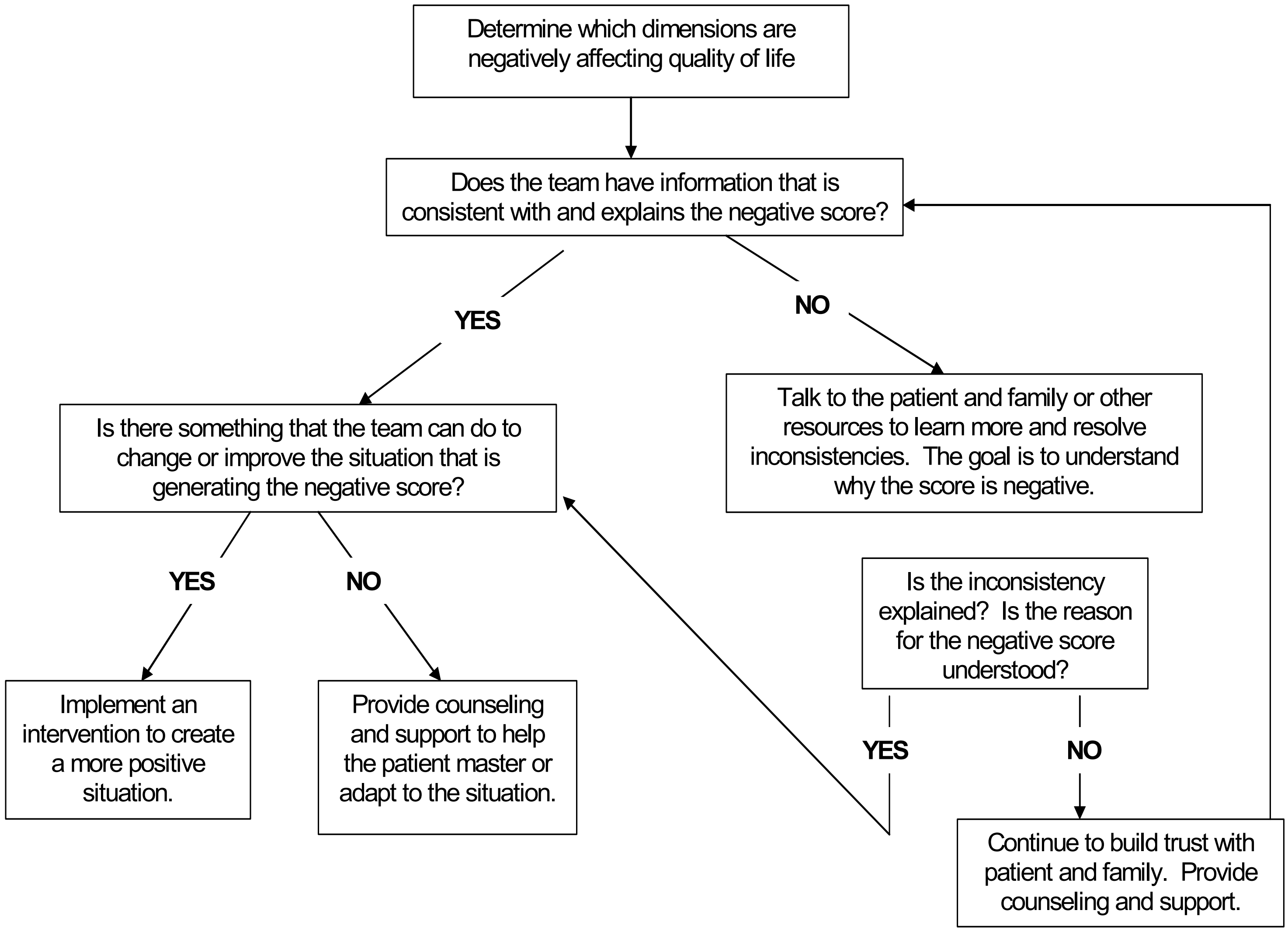
What is consistent?

What is inconsistent?

Then determine whether more information is needed from the patient or family to craft interventions that might improve quality of life.

The algorithm on the next page may help in using the MVQOLI quality of life profile.

Algorithm for Using the Quality of Life Profile



The following table provides suggested interventions in the case of low scores in a given MVQOLI dimension.

Domain	**Definition**	**Suggested Responses/ Interventions**
Symptom	**• Experience of the physical discomfort associated with progressive illness; perceived level of physical distress.**	**• Medication; other therapies; address non-physical factors contributing to symptoms; discuss of meaning of symptoms for patient; identify patient goals for relief.**
Function	**• Perceived ability to perform accustomed functions and activities of daily living; experienced in relation to expectations**	**• Medical equipment; "Occupational therapy"; identify and enable enjoyable activities; reframe current experience; caregiver education; increase CNA or volunteer.**
Interper-sonal	**• Degree of investment in personal relationships and the perceived quality of one's relations with family and friends**	**• Facilitate completion in relationships and personal affairs; facilitate communication with family (express and accept love/forgiveness); facilitate opportunities to contribute "wisdom"**
Well-Being	**• Self-assessment of an internal condition; subjective sense of wellness or "dis-ease"; experience of contentment**	**• Reframe current experience and social (family) role; discuss fear of being a burden and assist with additional caregiver support (volunteer or CNA); address fears and anxieties**
Transcen-dent	**• Experienced degree of connection with an enduring construct; degree of experienced meaning or purpose in life**	**• Life review; facilitate connection with spiritual or religious persons, books, experiences; facilitate opportunities to make contributions to others and/or to share "wisdom"**

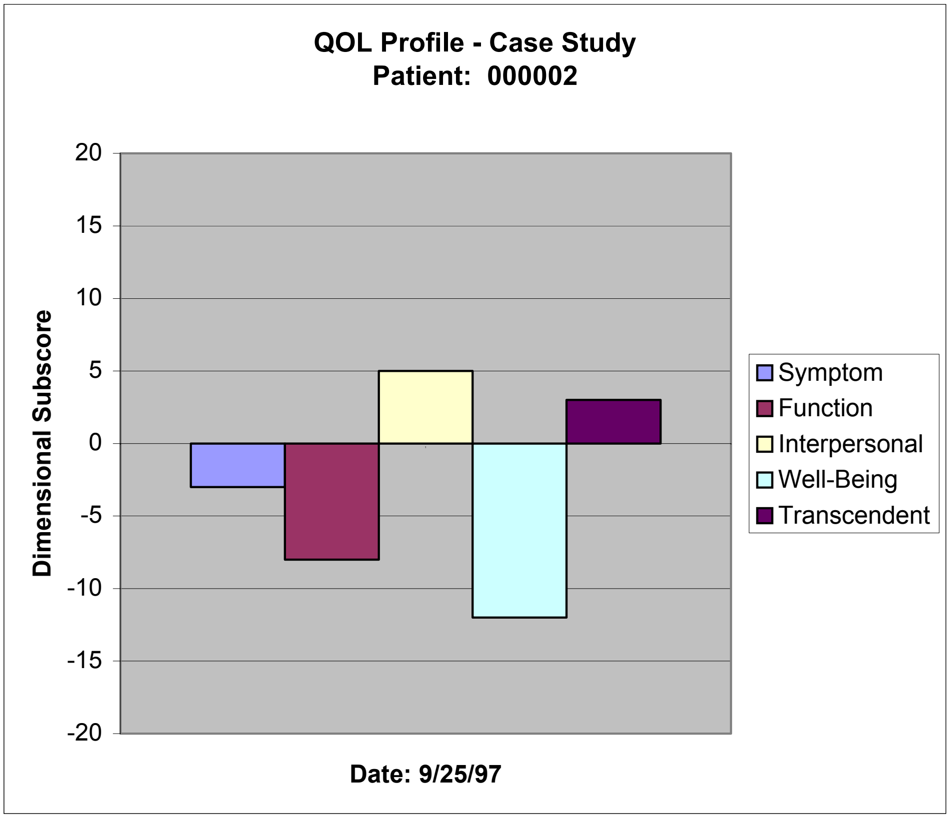
The case study on the next few pages demonstrates potential use of the MVQOLI information and the QOL Profile.

MVQOLI Case Study

Pt. 000002

The patient is a 74-year-old white female with malignant, metastatic melanoma. She lives with her son and his family, a wife and two daughters aged 10 and 13. She is at home alone during most of the day. On admission to Hospice three days ago, she reported a recent increase in back pain (she reports a pain level of 4 on a 0-10 scale) and weakness and dizziness that occurs in Aspells≅ throughout the day. She also had recurrent headaches which she attributes to the fact that she recently fell on her way to the bathroom in the middle of the night and hit her head. She is cheerful, ambulatory, and capable of basic ADLs.

Upon admission to Hospice, the patient completed the Missoula-VITAS[7] Quality of Life Index (MVQOLI).



Source: VITAS Healthcare Corporation

Interpretation of Profile:

Well-being is the patient’s largest dimension and is negatively impacting her quality of life. The next most important to the patient is functional, which is also negatively impacting the quality of life. The least negative dimension is symptom. The patient’s interpersonal dimension is more important at this time than transcendent and both are positively impacting quality of life.

Team Recommendations:

Based on the MVQOLI Patient Profile, the Hospice interdisciplinary team determined that the social worker will visit to assess the issues that are causing the patient the observed emotional distress (low well-being). The nurse will visit the patient to determine which symptoms are limiting function and which activities the patient most wants to be able to participate in.

Interventions:

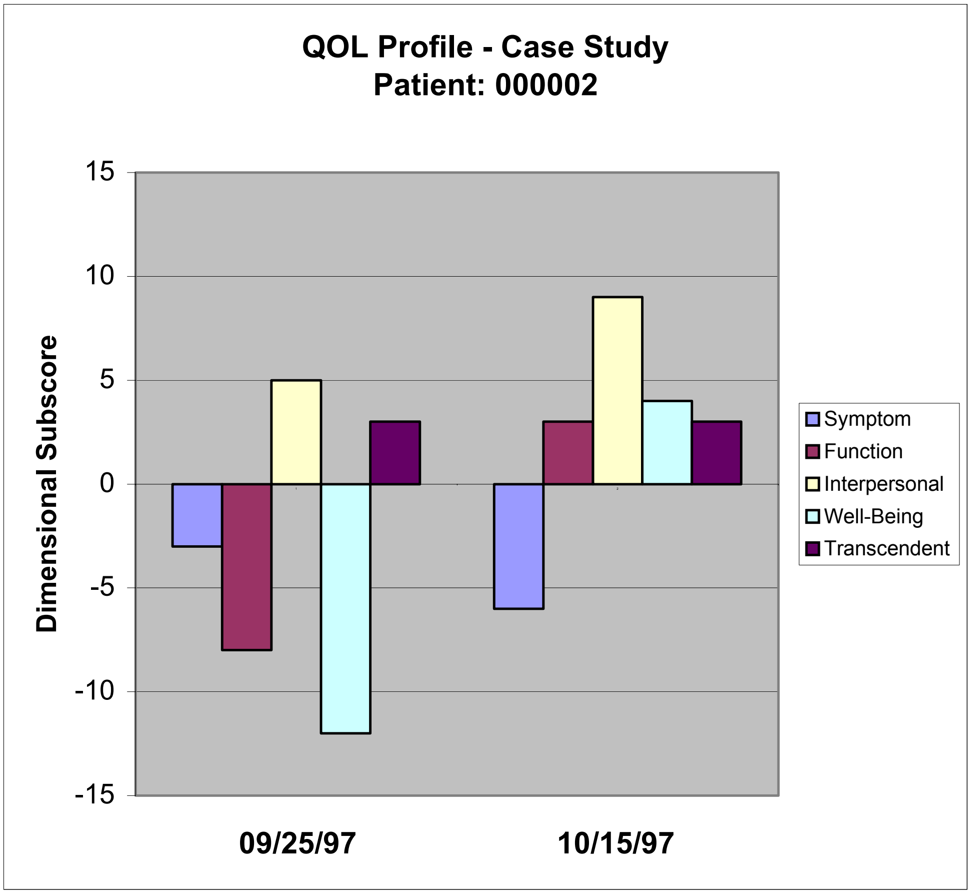
The Hospice social worker used the MVQOLI to guide the conversation, noting the patient’s negative responses to items about self-worth and about having her affairs in order. The patient reported that she feels she is becoming a burden on her son’s family because her declining physical state keeps her from doing the cooking, cleaning and child care that she used to do. She also feels more distant from her granddaughters because the whole family is trying to hide the fact that she is dying. The social worker set a meeting with the nurse to address the issue of declining physical state and then offered to facilitate a conversation between the patient and her son concerning her role in the family and how they might talk to the granddaughters about Grandma’s health.

The Hospice nurse addressed the patient’s desire to continue to help around the house and her fear that her back pain, weakness and dizziness might make it dangerous for her to use the stove or be alone with the children. The Hospice nurse and the attending physician worked together to manage the back pain with appropriate analgesic medications. They also suggested ways that the patient could continue to help with meal preparation by doing tasks while seated. It was also decided that a friend of the patient would be asked to come over some evenings to help with child care so that the patient could have time with the granddaughters while the parents went out.

Results:

After 18 days of care, the patient again completed the MVQOLI and her profile is on the next page.

Source: VITAS Healthcare Corporation



Team Assessment:

Although her symptoms continue to worsen, her activities have been adapted to her ability level and she is more accepting of her functional level. In addition, the quality of her relationships with the family has significantly improved. Her well-being has improved greatly.

Source: VITAS Healthcare Corporation

V. Repeat administrations of the MVQOLI to monitor changes in patient quality of life

Repeated administration of the MVQOLI is useful to the team and the patient. Clinicians report that patients sometimes ask to complete the tool a second time and that they are even more comfortable with the items and with follow-up discussions after the second administration.

A second or third administration of the MVQOLI allows the team to monitor the effect of their interventions. Typically patient quality of life improves in one or more domains while other domains may become more negative.

We recommend that the second MVQOLI administration be done between 18-24 days after admission. This is time enough for interventions and or disease process to have an effect, but short enough to allow a second MVQOLI for many hospice patients. For subsequent administration (3rd, 4th or 5th MVQOLI), we recommend 45 to 60 day intervals since patients who are in your service that long are usually changing less rapidly and become tired of repeated administrations.

While a regular protocol for administration is recommended, the MVQOLI can and should be used “off protocol” whenever the team feels that it will help them to serve the patient. The following checklist of information to cover may be useful in training and practicing repeat administration of the MVQOLI.

Administering the MVQOLI
Subsequent Surveys Check List

____ Ask the patient if they remember filling one the quality of life assessment a few weeks ago?

____ If they do not remember, go back to the original checklist and reintroduce the MVQOLI.

____ If they do remember, indicate that you want them to fill it out again so the team can see how things may have changed from their perspective.

____ Remind them that it is optional and that they can stop at any time.

____ Encourage participation by reminding them how useful the information is to the care team in personalizing care.

VI. Summary and Supporting Materials

The MVQOLI assesses quality of life from the patient's perspective and provides a graphic representation of five dimensions of quality of life. Dimensions that are positively affecting quality of life appear as positive bars above zero and dimensions that are negatively affecting quality of life appear as negative bars below zero. The care team can integrate this information with other data about the patient in order to craft interventions that may improve quality of life.

The steps in using the MVQOLI are:

1. Introduction and administration of the instrument with patients; and tracking of the use of the MVQOLI
2. Scoring the tool and turning the data into the quality of life profile
3. Interpretation and discussion of the profile with the clinical team to determine the best interventions
4. Re-administration of the MQVOLI with patients after several weeks and continued use in care planning and delivery

Supporting Materials

The following appendices are available for download at www.dyingwell.org/MVQOLI.htm

Appendix 1: MVQOLI - 15 item version with scoring information

Appendix 2: MVQOLI - 25 item version with scoring information

Appendix 3: Spanish MVQOLI - 15 item version with scoring information

Appendix 4: Spanish MVQOLI - 25 item version with scoring information

Appendix 5: EXCEL scoring program for MVQOLI - 15 item version **(English or Spanish)**

Appendix 6: EXCEL scoring program for MVQOLI - 25 item version **(English or Spanish)**

Appendix 7: MVQOLI EXCEL (automated) Scoring Instructions

Appendix 8: MVQOLI Manual (not automated) Scoring Instructions

Appendix 9: MVQOLI Date Due Excel File

Appendix 10: Instructions for the Date Due Excel File