The Impact of AIDS-Associated Wasting on Quality of Life: Qualitative Issues of Measurement and Evaluation¹,²

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In 1987, wasting was designated an AIDS-defining condition by the Centers for Disease Control (Centers for Disease Control 1987). Defined conventionally as the involuntary loss of 10% or more of one's premorbid weight, wasting has been observed as a primary feature of HIV disease since the first reports were filed documenting the clinical manifestations of this condition. The prevalence of wasting was reported to be approximately 17% through 1989 (Fleming et al. 1991); however, more recent clinical trials have documented that as many as 50% of people enrolled in AIDS studies have been found to have involuntary weight loss in excess of 10% of premorbid weight. The most recent reports find that wasting ranks as the second most frequent initial AIDS-defining condition in the United States and is diagnosed with equal frequency in men and women (Nahlen et al. 1993). As a cause of death wasting has increased from 3.6% to 13.7% during the period 1984-1995 as compared with pneumocystis carinii pneumonia which decreased from 28.6% to 3.8% (Kravik et al. 1997).

The clinical and quality-of-life implications of AIDS wasting are striking. Loss of 10% of body weight at the time of AIDS diagnosis, moderate (>4.5 kg) weight loss prior to an AIDS diagnosis and failure to regain weight after acute infection are all associated with decreased survival. Increases in the rates of hospital admissions and diminished quality of life have also been reported (Cohan et al. 1992; Turner et al. 1994). The mechanisms by which wasting exerts its influence on mortality and morbidity have not been fully elucidated. Reductions in lean body mass are correlated with mortality, while loss of body fat does not show the same degree of association. Loss of lean body mass leads to weakness, organ failure, secondary immune dysfunction, general inanition and ultimately death. A body cell mass of <30% is predictive of a survival rate of only 20% by about 15 months. This compares with over 70% survival at two years among individuals who maintain their lean body mass, an effect that is independent of CD4+ T-cell count.

Treatments for AIDS-associated wasting have led to the development of new treatments for enhancing weight gains in chronically ill patients. However, the functional and quality-of-life impacts of these treatments have not been well studied. Changes in body composition, rather than changes in functional patient status, have remained the primary endpoint. Measures of exercise tolerance and muscle strength have been the focus of most studies purporting to evaluate physical function. However, the mechanisms by which changes in weight and body composition affect how a patient feels emotionally, how able he/she is to carry out daily activities, and how he/she responds to social relationships have not been studied systematically. Implications for associated changes due to wasting and quality of life can have important implications for evaluating the relative importance of the clinical significance of new therapies. This paper will report findings from four focus groups conducted on patients with AIDS-associated wasting and highlight conceptual and measurement issues important for evaluating the therapeutic impact of pharmacological agents on AIDS-associated wasting.

DEFINING QUALITY OF LIFE FOR EVALUATION PURPOSES

Improving the patient's quality of life has been one of the major goals of a variety of nutritional and pharmacological therapies for AIDS-associated wasting (Von Roenn 1994). Defining the salient quality-of-life issues from the patient's perspective is one of the necessary steps in standardized assessments in clinical research. The term "quality of life", or more specifically "health-related quality of life", is used as an organizing concept that brings together a set of different health domains, each comprised of multiple dimensions, the two basic dimensions capturing function and feelings (Table 1) (Bergner 1989, Brook et al. 1979 and 1983, Levine and Croog 1984, Patrick et al. 1973...
and 1992). While objective components are important to defining each level of health, the perceptual domain translates these levels to the actual quality of life experienced by the patient. The expectations of health and the ability to cope with limitations and disability greatly alter an individual's perceived health and satisfaction with life. Because of the multidimensional nature of quality of life, there is an almost infinite number of states of health each associated with varying quality, and quite independent of the length of life. For example, an individual on a respirator without brain activity and with no promise of recovery would be deprived of even the lowest level of quality within each domain, while potentially living a relatively long life. Between this extreme and a long and fully healthy life, there exists a continuity in quality of life which underscores the rationale for its measurement (Testa and Simonson 1996).

The measurement of Quality of Life

Translating domains into a quantity that represents the continuum of quality of life is a complex task drawing from the fields of clinimetrics (Feinstein 1987), psychometrics and the health decision sciences. Spontaneous reports of adverse events as an indicator of life quality might be sensitive to highly toxic medications, but are relatively insensitive to the effects of those less toxic medications (Anderson and Testa 1994). Simply asking the patient a single question, such as “Please rate your quality of life or overall health on a scale from 1 to 10” leaves the definition of the “quality of life” or “overall health” totally defined by the respondent and the actual construct measured ambiguous and nonspecific for sample-based research. Most researchers attempt to measure each domain separately by asking several questions, which identify the domain’s most important dimensions. Variation among different quality-of-life evaluation techniques is more often related to their emphasis and extent of domain coverage, rather than real differences in definitions.

How does the researcher ascertain which domains are most important? One could adopt the approach that domains of health status and quality of life are universal, that they should include all aspects of functioning (mental, emotional, physical and social) that are important and relevant to human life. Once this approach is adopted, the problem is one of measurement, rather than definition. While health status and quality-of-life instruments have been commonly segregated into “generic” and “disease-specific” measures, the real difference between the two classes is the variability in the degree of emphasis and the depth of measurement among domains.

When investigating the effects of new pharmacological agents on AIDS-associated wasting, it is important to target the appropriate emphasis and depth that is relevant to the persons seeking treatment. One technique used to ensure that relevant areas have been targeted is to conduct structured patient focus groups. The following sections report the findings from four such focus groups conducted in persons with AIDS-associated wasting.

METHODS

Four focus groups were conducted by a licensed psychologist (W. R. Lenderking), two in New York city (10 men and 8 women, predominantly African-American and Hispanic) and two in San Francisco (a total of 16 men, predominantly Caucasian). Patients were recruited by local market research companies in New York and San Francisco, using in-house databases, recruitment through community groups and newspaper advertising. Participants were required to have a history of 10% weight loss below their ideal weight, and HIV infection. They were not required to be currently experiencing wasting. The first diagnosis of wasting ranged from one month to seven years ago. Participants provided their written informed consent to participation and being audio and video-taped, agreed to be observed, and agreed to hold the group discussion confidential. They were each paid $100 for participating in the groups, which lasted approximately two hours.

The focus groups were conducted using a semi-structured interview and were designed using a model of quality of life based on symptoms and perceptions of wasting, physical, psychological, social, and sexual functioning, and health perceptions as described previously. The interview was designed to allow participants to speak freely about how wasting had affected them in each of those areas.

Definitions of each domain were provided, and prompts were used if participants failed to mention an issue spontaneously that had been previously identified as relevant in the medical literature. For example, physical functioning was defined for participants as, the ability of your body to do the things you have to do, or want it to do. Prompts were suggested as follows: When you were experiencing wasting, how did that affect your fatigue, physical strength, and endurance? What activities did you have to give up? What was the most strenuous thing you needed or wanted to do, and how did wasting affect your ability to do that? Inquiries were made concerning one’s ability to perform basic activities of daily living (ADL’s) besides toileting, such as dressing, sitting, ability to kneel, and about intermediate ADL’s, such as walking a flight of stairs.

### TABLE 1

<table>
<thead>
<tr>
<th>Domains</th>
<th>Dimensions</th>
<th>Aspects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biomedical</td>
<td>Morbidity</td>
<td>Disease prevalence, laboratory values, clinical evaluations</td>
</tr>
<tr>
<td>Physical</td>
<td>Mortality</td>
<td>Length of life, survival time</td>
</tr>
<tr>
<td>Psychological</td>
<td>Somatic feelings</td>
<td>Pain, discomfort, neurologic and sensory deficits, fatigue, vitality, symptom prevalence</td>
</tr>
<tr>
<td>Psychological</td>
<td>Functional status</td>
<td>Eating, dressing, bathing, sleeping, mobility, sexual function</td>
</tr>
<tr>
<td>Psychological</td>
<td>Cognitive Function</td>
<td>Memory, psychomotor skills, alertness, reasoning, problem solving, concentration, orientation, judgment</td>
</tr>
<tr>
<td>Social</td>
<td>Relations</td>
<td>Family, friends, intimacy</td>
</tr>
<tr>
<td>Social</td>
<td>Work and Role</td>
<td>Occupation, avocations, productivity, absenteeism, recreation and leisure</td>
</tr>
<tr>
<td>Social</td>
<td>Functioning</td>
<td>Health</td>
</tr>
<tr>
<td>Perceptions</td>
<td>Life Satisfaction</td>
<td>Wellness, comfort, misery, suffering, health-related expectations, coping with limitation</td>
</tr>
</tbody>
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Contentment, comfort, happiness, expectations for life
carrying groceries or laundry, or engaging in moderate or vigorous exercise. Participants provided summaries of the aspects of their quality of life that had been most affected by wasting.

RESULTS

A total of eight hours of tapes were reviewed. Over 500 individual quotes were selected and grouped according to the major themes and quality-of-life domains identified by participants according to the conceptual framework outlined above. Commentary on each domain and representative quotes are reported below.

A. Symptoms and Perceptions of Wasting

As expected, participants emphasized weight loss as the major distressing characteristic of the wasting syndrome. In particular, they emphasized symptoms of fatigue, lack of energy, loss of appetite, exhaustion, night sweats, diarrhea, loss of muscle and strength.

"For me, wasting is losing a lot of weight."
"The most wasted I was I weighed 108 pounds exactly", said a woman who reported her usual weight as 140–150.
"I never was a big person—110 maybe 115 but when I went down to 88, mmm that hurts." My face had become kind of sagging, I had no definition at all, Flat butt. No muscle mass.”
"I looked like a little old man.

Although most people felt that a weight loss of 5% to 10% was the minimum for a definition of wasting, a few others felt that the definition was too lenient and that people should be treated sooner.

"I wish there was another criteria, another test, besides weight loss.”

For others, however, the magnitude and rapidity of the weight loss were characteristic.

"Mine came on rather quickly. It reached a point where my clothes were falling off... I noticed a loss of facial mass.”
"You’re going to go from a size 34 to a size 28 in a month’s time." Your body can’t hold your weight no more.”
"My regular weight is 145...there came a time when I went down to 110...people look at you funny.”

Some people definitely appreciated the distinction between weight loss and loss of lean body mass.

"The wasting had begun and I wasn’t even aware of how my body had begun to fail me... weight loss came afterwards... [I would] look at my arms, my hair... I was pretty healthy, I saw it, saw how my clothes fit.”

In spite of the general emphasis on weight loss, for many participants wasting was associated with lack of energy, loss of appetite and exhaustion characterized as totally debilitating.

"I went down to 98 pounds... no energy, didn’t want to eat... the smell of food made me sick!"
"Wasting would have to be psychologically, physically, and spiritually... You don’t go [die] because one thing goes, everything goes... wasting is holistic just as the virus is... muscle mass and tone... delineation... it all goes and you’re skeletal... Body functions start going... I’m not talking about fatigue, but where you can’t get up at all.”
"The most drastic thing was the look... then not being able to do for myself... . my face had literally drawn in.”
"For me, it was always looking down at my legs, and seeing that they were too skinny. After a while, it became a silent torment.”

However, there were individuals who did not emphasize the loss in weight as primary, and emphasized loss of appetite, diarrhea, or the functional disabilities caused by lack of energy:

"The bottom line is you don’t feel part of... food is good, everyone loves to eat... when food is in front of you and you don’t feel like eating... that’s not normal.”
"I’m totally disgusted with food... I would go days without eating.”
"Wasting for me body functions not functioning properly like they used to... not being able to do the things that I usually do like clean the house, walk up the steps.”

Having recovered from an acute episode of wasting, many people in these groups remained vigilant about their weight and their eating, fearing recurrence.

"I’m 150 and if I go to 149 I start wasting.”
"For me it feels like I’m wasting from the inside out... I feel good but I still don’t gain the weight. I have to concentrate on eating...”
"Having this sense of my body as my enemy. Looking at food and not wanting it... I am doing all these things making myself well, and why isn’t my body going along with it?”
"Wasting is the reality of AIDS.”

B. Physical Functioning

Physical functioning in individuals with HIV wasting is affected by several consequences of the syndrome, especially lack of energy, but also a sense of fragility, the level of motivation of the individual, and environmental factors. Nearly all participants reported functional limitations, some quite severe, due to lack of energy or muscle weakness. Many of the aspects of functioning related directly to a lack of strength and vitality. Participants reported lack of sufficient energy to perform daily activities, a loss of stamina and mobility, and an inability to perform satisfactorily at work. Others reported debilitating fatigue and loss of strength, which led to decreased function in intermediate activities of daily living such as shopping, as well as basic activities such as dressing and bathing. Driving, using public transportation and climbing stairs, were activities which participants reported were much more difficult when they experience wasting.

"I don’t have that energy... that’s what devastates me the most.”
"As much as your mind says you can do it, your body says no.”
"The loss of energy... affected all the other areas.”

Many activities at higher levels of functioning were impaired by wasting, including exercise and recreational activities, such as playing with a pet, dancing or traveling on an airplane.

"I can’t exercise... if I can do 3 [repetitions] I’m lucky, much less a set of 10.”
"I remember I got a new puppy around the time I was at my lowest weight and I couldn’t keep up with him and he was one of those that would take off in the park and I would
try to chase him and I remember coming home saying, "We've got to get rid of this dog, he's killing me."

"Dancing was really the only form of socializing or exercising that I had and it really, really curtailed it."

"I had a $200 American Airline voucher that I had to let expire because I didn't have the energy to go anywhere or do anything."

"I'm frightened to even try to exercise. I grew up on swim teams and I was thinking of trying to get back into that, but to this day I'm frightened of any kind of aerobic activity."

Wasting interfered with occupational functioning, and in some cases resulted directly in a change in work status, performance, dropping out of school or having to give up one's vocation all together.

"I had to drop out of graduate school... I didn't have the stamina to keep up... with my field work."

"I used to ride my bike [several miles to work] twice a week... I can't even ride a bike a block... I have no energy... after two weeks I thought I was going to die, I couldn't do the job."

"I used to have a catering business. It was too hard to cook."

"I gave up work against my will... too tired, People were noticing it... Too tired to push the chair back and go home."

"It finally got to the point where I physically couldn't do the work anymore. It's just really weak over long periods of time... I went from seeing a clientele of 350 people to no one."

"I used to be a cutter of women's garments. I don't think I could pick up even half a roll of that cloth now."

Though some individuals were still working, the loss of energy due to wasting had caused a significant reduction in the scope of their interactions.

"Just to get out [to work], you know, take my shower, do my hair, get my clothes together, by the time I get downstairs to my car you know I'm sitting there, I'm tired."

"Tired, no social life anymore. Get up, go to work, go home, that's it."

"[after work]... I'm coming straight home tonight."

"You work and you don't have a social life. It's one or the other."

Driving for some was a source of worry, for others an absolute necessity. Giving up driving due to physical disability is often considered surrendering independence. Individuals pay a very high price, both functionally and psychologically when they feel they must give up driving.

"I quit driving... I felt like I would kill somebody... don't have any strength, especially stepping on the brakes if somebody darted out in front of me."

"The last thing I was going to give up was my car. That's what keeps me from climbing the hill [on foot]."

The amount of weakness some experienced was profound, enough to affect all aspects of physical functioning. The exhaustion that accompanied wasting interfered with nearly every aspect of the individual's daily activities.

"It's called, You can't do it. You could do it before, now you can't do it... It's an effort to get out the bed. It's an effort to get to the bathroom. It's an effort for you to have to make your own meals, It's an effort... before it was just a natural thing that you did because you could get up and do it... climbing steps, forget it, that's a major, major job."

"Everything you used to do... like carrying groceries... is an effort... I get to the top of the stairs and It's rest time."

"When I climb stairs I'm out of breath when I get to the top."

"Cleaning... I have to rest... I can't walk... I live in a 1-bedroom apartment and I have to rest between each room."

"Going back and forth to the store... I used to carry two bags of groceries, now I can only carry one."

The sense of fragility associated with severe wasting affected mobility for some, but weakness, particularly in the hands, was also a problem in its own right. One woman talking about riding the subway said,

"... I need someone with me... if my legs collapse."

"I just can't do what I used to do. Coming here was a major deal... Now I have a sense of fragility more than anything else." (In a man who had gained 70 pounds and was still 30-40 pounds underweight.)

"I sit or lay in a place for some time and my bones hurt... they feel weaker."

"Carrying something would really ache me... you could sit there and... hold... something in your hand... and then for no reason your hand act like it want to shake... ."

"You forget what the little things mean to you, like opening a bottle and doing small things. There was a period when everybody had to do everything for me... turn on the TV, turn down the lights, flip the page. I hate that."

"You bruise so much more easily."

C. Psychological Functioning

Wasting also has a profound negative impact on the psychological functioning of many individuals. The sense that HIV is now out of control was reflected in their overall sense of psychological control. Participants reported that wasting evoked feelings of hopelessness, loss of power, grief, depression, preoccupation with morbid thoughts, anxiety, fear, panic and even anger. As reported by one female participant,

"I would rather be in the hospital with pneumonia and have my normal weight than go out in the street and be wasting, you understand me, so people will start looking at you because then people know, you get what they call, The Look."

Wasting was considered to be the first tangible sign that death is approaching. With that realization came a sense of depression, resignation, and hopelessness, but also for some, a time to prepare themselves for their demise.

"When you start wasting you lose the will to live."

"I felt powerless, no hope... you start thinking about death."

"When I first started wasting, the first thing I did was I decided I needed to get all my papers in order, and I went through and I just organized things and serialized things so that if I'm dead everyone will know what's up."

"It's beginning to wear a bit now, you know, the reality... [crying]"

"I cry sometimes because I had that gym body and I'm not going to get it back... you're gradually disappearing."

"... Depression was really bad. I called all my friends and said I was dying, gave all my jewelry away, I cashed in my life insurance. I went through $30,000 in two months,
Appearance was a major issue with many different psychological ramifications. A good appearance was linked to feelings of worth, self-esteem and value. The loss of one’s usual appearance not only diminished these feelings, but resulted in loss of role functions.

Increased anxiety and uncertainty are also brought on by wasting. The inability to predict the course of the syndrome seemed to be a primary cause of anxiety.

“You notice your pants are not fitting more and more each day, like the belt you have to go another hole, and if you don’t have another hole, you have to make one... as it progresses you get the idea of how you are now looking... strong fear with having to look at yourself deteriorate in front of your own face, and the doctors are telling you that there’s nothing they can do.”

“I look like E.T.’s sister... when I go down... I start panicking because it’s very easy for me to start wasting...”

Anger was less frequently reported, but there was clearly a significant amount of angry feelings about the condition for some.

“I had a tantrum and threw a metal chair across the room... I didn’t have an ass, I wasn’t going to sit on a metal chair.”

Having survived an episode of wasting leaves for many a residual feeling of unease about the possible return of the condition.

“I feel great right now, I look better than I ever have before... I have friends who were in the position I’m in and I watched them go totally backwards all at once. You never know what’s going to actually happen to you, so I do operate out of a great deal of fear.”

Appearance was a major issue with many different psychological ramifications. A good appearance was linked to feelings of worth, self-esteem and value. The loss of one’s usual appearance not only diminished these feelings, but resulted in alienation from one’s self, a sense of seeing a stranger in the mirror.

“If I look at myself in the mirror naked I’m like disgusted.”

“I didn’t want to look at myself in the mirror... it confirmed that I was dying.”

“When I start losing my appearance... it does something to my esteem.”

“It took me hours to get dressed for the group... I want to camouflage this.”

“My self-esteem is gone because my body is not what it was before at all. I feel like a 70 year old man and I shouldn’t feel like that. So I won’t wear... certain clothing... I haven’t gone out dancing in a couple of years...”

“I could hide parts of my body but not my face.”

Self-esteem was damaged not only by a deterioration in appearance, but also loss of role functions.

“With the loss of work, your self-esteem really goes down fast.”

“It totally destroyed any self-esteem I had. I’ve never had real high self-esteem anyway and turning into a toothpick definitely hurt... . . . My self-esteem reached the point where I was afraid to be around people because I looked so bad.”

For some, recovery from an episode of wasting brought great hope.

“As the wasting continued... I accepted my own demise. Now I just feel incredibly great that I’m here and I’ve been given a second chance, because that’s what it is.”

Many participants talked about the importance of maintaining a positive attitude in coping with AIDS, and how wasting in particular was a strong challenge to their sense of hope and faith. Marshaling psychological resources was important.

“It’s harder to have faith when you are going through something.”

“... A change of thinking is much easier to believe in when you are feeling good... there’s more of a challenge in keeping your faith in a Higher Power, or whatever your concept is.”

“I have to save what’s mine, what’s important for me.”

Cognitive functioning deteriorated as well for some participants during their episodes of wasting.

“I couldn’t remember what I was talking about, I’d be in a conversation and I couldn’t remember what I was talking about.”

“You get woozy, and sometimes you get more confused... you had to go an agency, you park the car, you had three bouts of diarrhea, it’s getting dark and now it’s like, Oh, where’s the car??”

Emphasizing the severity of the short-term memory problem, another man said in response, “No, where’s the agency?”

One man said it was harder to sleep because of his psychological reaction to wasting.

D. Social Functioning

Wasting affects social functioning in important ways, primarily due to the effects of having a wasted appearance to others and due to reduced energy and motivation for socializing. Social contexts for individuals with this disease differ greatly. For many, wasting syndrome caused the stigma of AIDS to become visible to others. Yet for others, wasting was the catalyst for greater closeness with selected groups of friends and family members. The primary areas reported were loss of social interaction, fear of rejection, being forced to hide the condition from friends, inability to form new relationships, social isolation because of fear of rejection and an inability to deal with the empathy expressed by friends and relatives. Participants also reported a reduced capacity to enjoy social interactions such as playing with grandchildren and dating.

“I was very blessed because any of the times I was
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challenged... those were the times that other people believed and I didn’t and that was really a blessing.”

“People are very visually-based, and if you’re well-looking... with this disease, people are like ‘Well you look fine to me, what’s the problem’. but there doesn’t seem to be a comfortable place in there anywhere, because if you go to the other extreme and you’ve wasted so much you look like a skeleton, and you’re on death’s door, people can’t handle that either... I was literally like an 85 year old person... it would take me 5 minutes to get out of a car. Just to see people dealing with that and to see that in a young man... I would catch them looking at me with such sorrow in their eyes, like ‘What a shame for all of this to happen.’”

“The physical inability to do what I wanted to do affected everything else and everyone’s reaction to me.”

Wasting affected how individuals interacted with others, as well as how they responded to strangers, friends, family or lovers.

“My weight loss totally changed my life. I am a hairdresser for a living. I would find myself doing psychological things to try to rationalize why this was all happening to my clients. I’d say whatever it would take to appease them because they could see what was going on and I didn’t want to admit it, I was in denial about it.”

“What bothers me is... the ignorant people that laugh and talk... a school friend I told before I told my family and I noticed the shy ness away from me.”

“Going out... I wait ‘til everybody’s good and drunk... so I can get compliments... if somebody says I’ve lost weight, that hurts.” “When I was wasted... I would go to the window to see who was there... I wouldn’t let anybody in... I couldn’t let a friend in because I lost a friend right there. They feel differently about me.”

“It was the reality for my friends that I have AIDS... the day I went back to work, I just got stared at. Nobody talked to me for two months... I just got looked at.”

Participants reported that wasting means that it becomes much harder to hide that one is sick, and one has to begin making explanations for one’s appearance.

“In our community... you can’t let anybody know... you have to make up another disease... diabetes... cancer is better [to explain why you’re losing weight].”

“According to people at work, I have cancer. I work in a very homophobic environment and would have to leave work immediately... I can’t hide the fact that I am losing weight.”

“Nobody in my family knows... when I was wasting... I just told them it was old age.”

Several individuals stated that wasting interferes with the formation of new relationships, the deepening of old relationships, and changing bad relationships, both because of appearance and lack of energy.

“Wasting kept me in a bad situation, in a bad relationship... because I couldn’t sell myself to nobody else. My self-esteem was through the floor... Who’s going to go out on a date with Skeletor?”

“Every conversation I have turns medical... People come up and say ‘How are you feeling?’ not ‘How are you?’”

“I have had several people say to me that they have lost so many friends to AIDS, that they have reached a point when they see someone getting sick they want to run away from it because they don’t want to experience that loss again... It makes me more aware of what a burden I must be.”

“Just walking down the street... lived here almost 20 years, and I see people that I’ve met and I look at them and I just know the changes they have been going through... then when I see somebody I know, like that I met at a party and I remember them, and they don’t make eye contact, and they don’t stop and I imagine that they know that about me and they’re uncomfortable and that’s why they’re avoiding any kind of contact. That whole scenario is ugly and distasteful... I don’t like feeling that way on either side.”

“I’ve lost very close friends that have turned away. They’re afraid I’m going to die and they just can’t handle that. There was no other reason for it. We’ve been close for years and years.”

“There was no sort of casualness to my relationships any longer. It was either people I knew or people I just didn’t deal with anymore.”

“My wife... she thought I was on drugs which I wasn’t. I was depressed a lot and I... shun away from them... by myself all the time... we didn’t have sex... I don’t know how my kids will take it if and when I tell them. I love my kids and grand kids and I don’t know if they will let me in the house.”

Even family members who are accepting of the disease and its manifestations are affected because of the increased household responsibilities.

“It’s a burden on my daughter.”

People sometimes interpret the weight loss as the sign of something else.

“I was accused of doing drugs for 6 months.” [by his family]

The apparition of AIDS as evidenced by the wasted appearance caused one’s health to become a focus of interaction, which became quite a burden at times.

“ ‘I didn’t want to deal with educating them about the fact that it isn’t all about the fact that I haven’t been eating enough.’

“It’s not that you don’t look good enough anymore. It’s that you have to deal with their dissatisfaction about the way you look.”

“Before you were diagnosed wasting, you had friends, you had family, they cared.”

“I don’t like pity... It’s overwhelming at times.”

“Everybody’s on eggshells.”

“My daughter, she would wait on me hand and foot... she was really concerned about me. She was very timid about touching me and stuff like that... it was out of fear, she thought she could break me.”

“When I was down to 98 pounds, I could see in friends and relatives their faces, they thought I was going to die... so then I stopped putting... a lot of energy into relationships.”

Dealing with the sorrow of others was sometimes overwhelming.

“For me the psychological thing was probably the worst. I’m kind of active in my church and I was there a great deal, and it got to the point where everyone would grab me and hug me and start crying, so I would isolate... see just a small group of people that I felt safe in seeing.”


"My brothers... around me were crying... it was depressing. I called up the funeral home and ordered my casket... I wanted a Jackie Onassis casket."

Dating and meeting people was certainly more difficult.

"I had an instance where... I do AOL to meet people. I met this guy online, we exchanged pictures on-line, and the picture was about 3 or 4 months old... I was starting to waste... The first question was 'How much weight have you lost?' Then, 'You look a lot different than your picture'.... Now I put on 30 pounds and he smiles and I just keep walking."

People found ways to cope with their wasting to maintain important relationships. One woman, who used to pick up her granddaughter, said, "I can't lift her... I sit on the bed and let her come to me."

The participants talked about how it affected their ability to travel.

"I put off trips now. Especially places where the food may be different because I'm concerned that I don't want to have to skip a meal. I want to make sure that I can eat, and eat as much as I normally do."

It was apparent that even living circumstances were influenced by the syndrome:

"It chose my housing... [I] live in a flat place, with a bus running 24 hours."

E. Sexual Functioning

Most participants expressed an overall loss of libido, feelings of shame and guilt, reduction in sexual drive, embarrassment concerning appearance to the point of severe inhibition and a general decrease or complete elimination of sexual energy. None of the women reported improvement in their sex lives as a result of wasting. Several men, however, reported receiving more offers for dates and sex.

"If you don't have sexual interest in other people, then you're wasting... you're not doing what normal people do every day."

"You don't feel sexy. I used to have a nice body... now I try to cover it up... have 17 pairs of pants that don't fit me, sizes 7 and 8, I wear size 3 now."

"If you're not with it, you're just not with it... My sexuality as a woman was very important to me... it was what I lived for... it was because of the wasting I'll never get it back... Watching movies that's the best it gets... I can't perform and I don't want to fake it."

"When you're wasting you ain't thinking about no sex."

"You don't feel good about you no more... so you really don't want to be undressed in front of nobody."

"Getting sick and looking sick... there is such shame, such deep-grounded shame that you don't want anybody to touch you. When you have sex... you feel like you're drained... you want to rest all day... you're drained. At one time I used to go through foreplay... [now I don't]."

"Because of the shame and guilt that I felt—there was a belief that said you're going to be OK, and there was a belief that said you're going to die... I went on a... sex run. I would go and have anonymous sex with a lot of people and then go home... I didn't want to deal... with my reality... when I was wasting... it wasn't sexual drive... I couldn't have an orgasm."

"You don't have that look of love."

"I have none... we're going to be working on a plan of action, because my drive is zippo."

"I got really, really depressed... lost my sex drives... In another study, where they were checking CMV load in semen, it was a chore to get the sample."

"Taking my clothes off in front of somebody is embarrassing."

"There's always a sexual energy that's around... joie de vivre... But you start wasting, guess what, there's none for you. You walk in the room, it stops. There's no flirting, nobody's going to flirt back with you, and if they are, you know it's pity flirting."

"My own partner wouldn't touch me, didn't want nothing to do with me."

"Do you want to have sex with somebody that looks sick?"

SUMMARY

Four focus groups were conducted in men (n = 26) and women (n = 8) with a history of HIV wasting, two in San Francisco of men only, two in New York City, one of men only and one of women only. Participants reported that HIV wasting has a profound negative impact on quality of life. The negative effects on quality of life were mediated primarily by the impact of loss of energy, changes in appearance, and GI symptoms on the important domains of quality of life, including physical, psychological, social, sexual functioning, and health perceptions.

Generic measures of quality of life, while covering the appropriate domains, fail to provide the sensitivity and depth required to evaluate the major issues raised by the focus group participants with respect to the specific impact of HIV wasting on their lives. Most generic instruments provide coverage with respect to physical functioning such as ability to climb stairs and carry groceries. They also measure psychological components such as anxiety and depression. However, condition-specific items more salient to persons with AIDS-associated wasting should focus on those areas of psychological and emotional impact not typically covered by standard generic instruments. As reported in this study, negative feelings about physical appearance, shame, embarrassment, social isolation, loss of appetite, loss of sexual libido, grief, fear, loss of self worth and self-esteem, hopelessness, cognitive dysfunction and difficulty sleeping were all linked to the wasting condition. Seemingly small improvements in appearance could potentially lead to large gains in self worth and self-esteem which would likely decrease social isolation and feelings of embarrassment and shame. Similarly, relatively small gains in muscle strength might enable one to open a jar, lift a bag of groceries or take a subway.

It was clear from these focus group that simply measuring increases in lean body mass or exercise endurance are inadequate metrics of improved health and quality of life for the evaluation of new therapeutic agents for AIDS-associated wasting. This lack of sensitivity in measurement makes it extremely difficult to detect new therapies that might benefit patients in profound ways.

How does one define "optimal patient outcomes" for purposes of the evaluation of new therapies for persons with AIDS-associated wasting or other diseases and conditions. The American Medical association defines optimal patient outcomes as,

"Optimal possible improvement in the patient's physiologic status, physical function, emotional and intellectual performance and comfort at the earliest time possible consistent
Health outcomes should therefore focus not only on the biomedical parameters which signify therapeutic efficacy, but on the specific interests of the patient. While clinicians communicate with patients on a daily basis, it is disconcerting that the products of that communication seldom form the basis for biomedical research. Semi-structured focus groups in patients with specific conditions are a useful method for translating the best interests of the patient into therapeutic research and goals.

LITERATURE CITED


