The Emotional Roller Coaster:

Psychosocial Challenges Faced by Patients with VHL and Techniques to Manage Them

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I. Psychosocial Challenges of VHL

II. Managing Distress

III. Empowerment
I. PSYCHOSOCIAL CHALLENGES
Is VHL a Challenging Experience?

YES!

• When is it challenging?

• …When is it not!
The Challenges

Anxiety & Worry

- Facing the on-going reality of:
  - Developing new tumors
  - Need for surgery
  - Family member developing VHL related tumor

- Dealing with complex medical information
✓ Worry, often about health
✓ Fatigue
✓ Difficulty sleeping
✓ Irritability
✓ On edge
✓ Interferes with social or work activities
Factors Associated With VHL Related Worries

- Diagnosed with/treated for VHL
- New/old symptoms
  - Higher levels of distress seen with patients who engage in high health surveillance without accessing healthcare
- High perceived risk of developing tumor
- Scans, follow-up appointments "SCANXIETY"
- High levels of social constraint
- Experienced the loss of a close relative with VHL during adolescence
The Challenges

- Frustration
- Anger
- Negative Thinking
- Denial
- Guilt

"He criticizes everything - the food, the staff - everything! So I've put him on the critical list."
The Challenges

Depression

✔ Feeling down
✔ Lack of interest in activities & people
✔ Less pleasure
✔ Changes in sleep, appetite, memory
✔ Everyone around you seems happier than you
Factors Associate With VHL Related Distress

- Female gender
- Increased risk factors
- High perceived risk of developing tumor
- Experienced the loss of a close relative with VHL during adolescence
The Challenges of Emotional Distress

- Lower social functioning
- Greater functional impairment
- Poor QOL
- More somatic complaints
  - Sleep disturbance, fatigue, pain
- Associated with unhealthy behaviors
  - Smoking, sedentary lifestyle, overeating, poor medical compliance
The Challenges
It’s a Family Affair

- Relationship strain
- Maintaining isolation
- Motivating patient
- Own mood changes
- Compassion Fatigue
- Role demands
What is the biggest single mistake that Caregivers make?
NOT TAKING CARE OF ONESELF!

No joking matter…
work
family
finances
caretaking

STRESS!
Stress - Who Experiences It?

- Everyone!

- Increased in VHL families
  - Increased in those diagnosed with or at risk of developing VHL
  - Increased in those not diagnosed with VHL

- Higher rate due to unpredictability of disease

- Should be considered 6\textsuperscript{th} vital sign

(Lammens et al, 2010)
DISCUSSION: PSYCHOSOCIAL CHALLENGES OF VHL
II. MANAGING DISTRESS
<table>
<thead>
<tr>
<th>Stressor</th>
<th>Controllable</th>
<th>Uncontrollable</th>
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<tr>
<td><strong>Coping Strategies</strong></td>
<td><strong>Problem-Focused</strong></td>
<td><strong>Emotion-Focused</strong></td>
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<td><strong>Active</strong></td>
<td>Get more Information</td>
<td>Reappraise the situation</td>
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<td>Set goals</td>
<td>Reframe thoughts</td>
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<td>Engage in focused activities</td>
<td>Do something to feel better in the moment (Exercise, massage, meditation, mindfulness).</td>
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<td>Ask for help</td>
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<td>Resolve conflicts</td>
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<td>Make decisions</td>
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<tr>
<td><strong>Avoidant</strong></td>
<td>Behavioral Avoidance</td>
<td>Escape Avoidance</td>
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<td></td>
<td>Cognitive Avoidance</td>
<td>(Smoke, drugs, drink, eat, sleep)</td>
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<td></td>
<td>Denial</td>
<td>Stop caring for yourself</td>
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<td>(Don’t think about it,</td>
<td>(Don’t take medication, miss appointments)</td>
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<td>don’t take steps to work on it)</td>
<td><strong>Stuff Feelings</strong></td>
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(Kilbourn, K. 2014; Carver & Scheier, 1994)
Express Emotions

- Talk to supportive others about thoughts and feelings
  - Helps to process change
  - Helps to confront negative emotions in safe environment
  - Helps to broaden perspectives, by hearing what others have to say
  - Reinforces self-esteem

(Stanton et al., 2002)
Express Emotions

- Journal thoughts and feelings

- Allows you to take a “time-out” for yourself
- Allows you to control when and how long you want to think about or write about your concerns/worries
- Allows you to accept concerns/worries without judgment
- Grants you permission to release concerns/worries
Express Emotions- Health Benefits

- Positive emotional adjustment
- Less intrusive thoughts, distress
- Less physical complaints
- Fewer hospitalizations

Support Groups, Online Forums, Therapists, Clergy, Journaling, Posting

(Stanton et al., 2002)
Acceptance

- Accept your reactions and be present
  - Allow thoughts to come and go without struggling with them

- Choose a valued direction
  - Discover what is important to you

- Take action
  - Set goals according to values and carry them out responsibly
Unhelpful Thinking Styles

- **All-or-Nothing Thinking/Overgeneralization:** “I can’t do the things I used to do, I’m useless.”
- **Fortunetelling/Catastrophization:** “The results will show the cancer is back.”
- **Disqualifying the Positive/Magnifying the Negative:** “I do not function sexually as I used to. Now my partner will not love me as before my treatment.”
- **Emotional Reasoning:** “I feel scared, something bad is probably going to happen.”
- **Labeling:** “What a jerk!” “I’m stupid.” “That meeting was a total waste of time.”
- **Mind-reading:** “He thinks I’m exaggerating” “They look at me like I’m contagious.” “She doesn’t want to hear about my problems.”
- **Personalization:** “My spouse is depressed, and it’s my fault.”
- **Unhelpful rules/Should and Must statements:** “I should not ask for help” “If people care about me, they ought to be able to tell I need help.”
- **Maladaptive Thoughts:** “I will never look the same again.”

(Beck, 1995)
Unhelpful Thinking Styles

- **All-or-Nothing Thinking**: “I can’t do the things I used to do, I’m useless.”

- **Catastrophizing**: “It will all go wrong for me.”

- **Should and Must statements**: “I should not ask for help.” “If people care about me, they ought to be able to tell I need help.”

(Beck, 1995)
Challenge Unhelpful Thinking

- Thoughts are not facts

- Be Aware

- Examine Evidence

- View the Alternatives

- Understand the Implications

(Beck, 2008)
Promoting Positive Thinking

- Make higher quality of life a priority

- Purposely enhance positive emotions
  - Pay attention to when/why you feel happy
  - Increase pleasant events that prompt + feelings (make a list)
  - Look for + meaning in your experiences
  - At the end of each day…
    - What was the happiest moment today?
Coping With Negative Thinking

- Use Thought Stopping
  - Pay attention to thoughts that brighten your spirits
  - Don’t attach too much importance to negative thoughts
  - Distract yourself from negative thoughts

- Try to maintain a positive outlook but don't feel guilty if you have down times
- No one is positive all the time!
II. DISCUSSION: MANAGING DISTRESS
III. EMPOWERMENT
Healthy Living

- While making healthy lifestyle choices such as eating a nutritious diet, exercising regularly, and stopping tobacco use is important for everyone, it is especially important for VHL patients.

- Staying in touch with and getting the most out of your visits with primary care and VHL care teams are important ways to stay healthy.
Healthy Living

Eat well

- Plant-based diet (5-9 servings of fruit and vegetables per day)
- Try to include beans and whole grains (cereals, bread, pasta) several times per day
- Choose foods low in fat and salt
- Get to and stay a healthy weight
Healthy Living

- **Exercise and stay active**
  - Research suggests that staying active after cancer can lower the risk of recurrence and lead to longer survival.

- **Moderate activities**
  - Walking quickly, biking, housework
  - Breathing hard but still able to talk

- **30 minutes of moderate activity per day can**:
  - Reduce anxiety and depression
  - Reduce fatigue, pain, nausea, and diarrhea
  - Improve heart health
  - Reduce weight
  - Increase feelings of optimism

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Start Low, Go Slow...

Even small activities like sitting upright, stretching your arms, or moving your legs count as activity. It is important to **start your exercise program slowly and increase activity over time**.

**Tips...**

- Start with 10 minutes of walking/day and build up
- Exercise while doing daily activities (TV, chores)
- If you have fatigue, exercise when you have the most energy
- Find an exercise partner that keeps you motivated

National Cancer Institute 2014
Getting The Most From Your Follow-Up Visits

Before you go:

✓ Bring paper to take notes
✓ Bring a family member or friend to help you remember, understand, or ask additional questions
✓ Make a list of questions ahead of time and bring it with you
Getting The Most From Your Follow-Up Visits

At your visit:

- Ask your most important questions first
- Express yourself clearly and describe the problem clearly
- Ask for what you need/want: “I am tired most of the day. I’ve tried napping but it doesn’t help and gets in the way of my daily life. What can be done to help?”
- Ask the doctor to explain in terms you understand
- Repeat back in your own words what you heard and ask for clarification
Getting The Most From Your Follow-Up Visits

➢ Before you leave

✓ Ask the doctor or pharmacist about the best way to take your meds and about side effects
✓ Don’t be afraid to ask for more time when you schedule your next appointment
✓ Ask for supportive resources in the area
✓ Keep your own set of records about any follow-up appointments you have
Questions About Your Follow-Up Plan

- How often should I see my doctors?
- What follow-up tests (MRI, CT, Blood) should be done?
- Are there specific symptoms I should watch for?
- If I develop these symptoms, who should I call?

Doctor’s Name/How often

Test/How often

Symptoms

Contact

National Cancer Institute 2014
Stress Management

- Relaxed Breathing
  - Learning to breathe like a baby
- Positive Imagery Rehearsal
  - Visualizing a peaceful moment like a movie
- Progressive Muscle Relaxation
  - Learning to relax all the muscle groups of the body
- Mindfulness Meditation
How Do I Know If I Need Professional Help?

- Symptoms of anxiety or depression that persist for > 2 weeks
- Symptoms negatively impact relationships or functioning at work
- An inability to make decisions
- Poor sleep or sleeping too much
- Irritability or feeling on edge
- Feelings of despair or hopelessnesslessness
- Feelings of worthlessness
- Constant thoughts about death
- You want more support
There is Good News!

✓ Come to terms with VHL
✓ Address fear of developing VHL related tumor
✓ Learn methods of coping with DNA test result
✓ Support in managing grief associated with the loss of a family member due to VHL
✓ Seek at high distress periods: at diagnosis, at VHL related surgery, and at/or immediately after DNA test results
III. DISCUSSION: EMPOWERMENT