# COURSE 16: PSYCHOSOCIAL IMPLICATIONS IN PATIENTS WITH VASCULAR ANOMALIES

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## Introduction: Psychosocial implications in patients with vascular anomalies


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Patients or parents of patients with vascular anomalies frequently appear as medical nomads, wandering from doctor to doctor in order to receive an accurate diagnosis and appropriate treatment. This process can be fraught with misdiagnoses and frustration for the parent as well as the patient. If the parent/patient is lucky enough to find a physician with expertise in the diagnosis and treatment of a vascular anomaly, they may find the experience of identifying someone who understands the psychosocial implications challenging.

Since 10% of all infants are diagnosed with a vascular birthmark, and 10% of those have one so significant that they need the opinion of a specialist (1%), it is no wonder that the psychosocial component is often overlooked.

Regardless of the fact that only 1% of those born with a vascular birthmark need the opinion of a specialist, every child born with, or every adult living with a vascular birthmark deserves both a medical and psychosocial evaluation.

Physicians should refer patients diagnosed with a vascular birthmark as soon as possible, to qualified specialists and to multi-disciplinary treatment centers to ensure the most favorable outcome. The psychosocial component should also be considered with these referrals. Unfortunately, while the psychosocial area is a primary concern to patients because it affects their daily experience, it is rarely addressed.

Very few, if any, physicians are trained in assessing the psychosocial implications to the patient/family.

This module provides insight into parents/patients' psychosocial experiences with dealing with a vascular birthmark, and suggests ways to raise physician awareness of the psychosocial impact of vascular anomalies on patient lives. The module details best practices in supporting patients' psychosocial health. It also suggests a number of referrals for support services and reviews psychometric instruments that can be used to assess patient/parent stress for dealing with this medical condition. There is also a brief exploration of assessment instruments. While the physician is not intended to make a psychological appraisal of the patient and/or the patient's family, it is important that the physician be familiar in assessment instruments and their purpose.

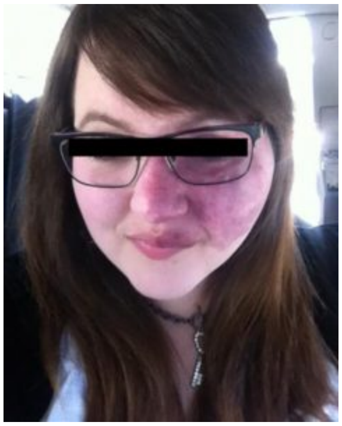
# Objectives

Upon successful completion of this activity, participants
should be able to:

- Identify common psychosocial issues for individuals living with vascular anomalies and their impact on larger patient issues
- Explain the approach necessary to provide psychological preparation for procedures
- List potential coping strategies and therapeutic strategies to support patients' psychosocial needs
- Provide supportive, engaging resources for patients and families
- Describe psychometric instruments used to assess the impact on the family/patient

# Psychosocial implications for parents and/or patients with vascular anomalies

Any vascular anomaly that results in the disfigurement of the face and/or body can have a devastating effect on the entire family system as well as on the self -esteem of the individual living with the vascular birthmark. Furthermore, depending on the visibility and extent of the disfigurement, some individuals will experience ostracism, avoidance, a lack of intimacy, discrimination, depression, and isolation. Children, teens, and even adults are often the target of bullying. Also, the visible presence of a vascular anomaly at birth can interfere with the normal bonding process. Precious time that should be spent enjoying milestones is spent wandering from doctor to doctor in search of an accurate diagnosis and appropriate treatment options.



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To effectively treat a patient and/or the affected family, it is critical that the assessing physician attend to not only the physical dimensions of the disfigurement, but also be aware of the psychosocial implications. Appropriate care of patients and their families should always include addressing the psychosocial and emotional impact of the medical condition on the patient and the family system, in accordance with all parts of the treatment process.

# Psychosocial interventions

Psychosocial interventions help to mitigate the negative psychological impacts of a

patient’s experience. Psychological preparation:

- Reduces recovery time
- Reduces stress
- Helps alleviate anxiety
- Yields better adherence to physician instructions across the lifespan

It is important to identify the specific stressors for the patient and provide strategies which allow the patient to cope with the specific stressor. Support for patients’ families is equally important. The stress that accompanies living with a condition not only has an impact on the patient but also on the larger family system.

Medical professionals should always address the impact of the condition on social situations where living with a visible difference may be most disruptive and encourage therapeutic activities, social support, and access to resources.

Such interventions may include trying to mitigate social difficulties of a new environment, reduce anxiety and ensure understanding regarding a treatment protocol, or help an individual receiving a new diagnosis to understand its implications.
Is it a stressful event when the parents of a child with a vascular anomaly are told that the lesion could become large, disfiguring, problematic, or even life- threatening? The Impact of Events Scale (IES) could possibly answer that question. Developed by Horowtiz, Wilner, and Alvarez (1979), the IES measures current subjective distress related to a specific event, such as the diagnosis of a vascular anomaly that is problematic, disfiguring, or even life-threatening.

# Patients' experiences

Patients' experiences with diagnosis and treatment are comprised of many elements, including:

- A range of emotions: embarrassment, ambivalence, anger, fear, and/or guilt. (Physicians and therapists should allow honest expression and validation of patients' responses as normal.)
- These emotions may focus on a sense of guilt, feeling responsible for the additional burdens that their illnesses place on parents, siblings, and the family system.
- A patient may also experience a feeling of difference or isolation; a feeling of the lack of control may also characterize a patient's experience. (Patients did not choose this experience.)
- Some patients experience insensitive treatment and comments, questions, staring, or bullying.
- Some patients may struggle with emotions surrounding acceptance of self "as is" vs. a desired change.
- Additional concerns include the progression of the condition, and specific impacts of the condition which result in increased pain or increasing limitation, experiences across the lifespan, and developmentally specific impacts of the condition on normative development.

## Hemangioma Reaction Questionnaire

**DIRECTIONS:**

Recall the stressful events that occurred in your life when your baby was diagnosed with a hemangioma.

**Briefly describe the one event that was the most disturbing (type your answer in this blank area. Try to keep it to 5 or 6 single spaced lines, if possible):**

________________________________________________________________

________________________________________________________________

________________________________________________________________

________________________________________________________________

**How disturbing was this event to you? (Please mark one):**

Not at all disturbing ____

Somewhat disturbing ____

Moderately disturbing ____

Very disturbing ____

Extremely disturbing ____

**DIRECTIONS: Below is a list of experiences people sometimes have during and after a stressful event. Please read each item carefully and decide how well it describes *your* experience following the diagnosis of your infant's hemangioma. Refer to this event in answering the items below. Use the 0-5 point scale shown below and circle the number that best describes your experience. Place an "X" or a check mark before the number that you are selecting.**

**0———————1———————2———————3———————4——————5**

| **0** | **1** | **2** | **3** | **4** | **5** |
|---|---|---|---|---|---|
| **not experienced** | **very rarely experienced** | **rarely experienced** | **sometimes experienced** | **often experienced** | **very often experienced** |

1. I had difficulty falling or staying asleep. _0 _1 _ 2 _ 3 _4 _5

2. I felt restless. _0 _1 _ 2 _ 3 _4 _5

3. I felt a sense of timelessness. _0 _1 _ 2 _ 3 _4 _5

4. I was slow to respond. _0 _1 _ 2 _ 3 _4 _5

5. I tried to avoid feelings about the hemangioma. _0 _1 _ 2 _ 3 _4 _5

6. I had repeated distressing dreams of the hemangioma. _0 _1 _ 2 _ 3 _4 _5

7. I felt extremely upset if exposed to events that reminded me of an aspect of the hemangioma. _0 _1 _ 2 _ 3 _4 _5

8. I would jump in surprise at the least thing. _0 _1 _ 2 _ 3 _4 _5

9. Thoughts of the hemangioma made it difficult for me to perform work or other things I needed to do. _0 _1 _ 2 _ 3 _4 _5

10. I did not have the usual sense of who I am. _0 _1 _ 2 _ 3 _4 _5

11. I tried to avoid activities that reminded me of the hemangiomas. _0 _1 _ 2 _ 3 _4 _5

12. I felt hypervigilant or "on edge". _0 _1 _ 2 _ 3 _4 _5

13. I experienced myself as though I were a stranger. _0 _1 _ 2 _ 3 _4 _5

14. I tried to avoid conversations about the hemangioma. _0 _1 _ 2 _ 3 _4 _5

15. I had a bodily reaction when exposed to reminders of the hemangioma. _0 _1 _ 2 _ 3 _4 _5

16. I had problems remembering important details about the hemangioma. _0 _1 _ 2 _ 3 _4 _5

17. I tried to avoid thoughts about the hemangioma. _0 _1 _ 2 _ 3 _4 _5

18. Things I saw looked different to me from how I know they really looked. _0 _1 _ 2 _ 3 _4 _5

19. I had repeated and unwanted memories of the hemangioma. _0 _1 _ 2 _ 3 _4 _5

20. I felt distant from my own emotions. _0 _1 _ 2 _ 3 _4 _5

21. I felt irritable or had outbursts of anger. _0 _1 _ 2 _ 3 _4 _5

22. I avoided contact with people who reminded me of the hemangioma, including my child. _0 _1 _ 2 _ 3 _4 _5

23. I would suddenly act or feel as if I had learned about the hemangioma all over again. _0 _1 _ 2 _ 3 _4 _5

24. My mind went blank. _0 _1 _ 2 _ 3 _4 _5

25. I had amnesia for long periods after the hemangioma diagnosis. _0 _1 _ 2 _ 3 _4 _5

26. The hemangioma caused problems in my relationships with other people. _0 _1 _ 2 _ 3 _4 _5

27. I had difficulty concentrating. _0 _1 _ 2 _ 3 _4 _5

28. I felt estranged or detached from other people. _0 _1 _ 2 _ 3 _4 _5

29. I had a vivid sense that the hemangiomas was being diagnosed all over again. _0 _1 _ 2 _ 3 _4 _5

30. I tried to stay away from places that reminded me of the hemangioma. _0 _1 _ 2 _ 3 _4 _5

**On how many days did you experience any of the above symptoms of distress? (Please mark one):**

none ____

one ____

two ____

three ____

four ____

five or more ____

# Psychological preparation

Psychological preparation refers to the strategies undertaken to adequately equip a patient/family member to cope emotionally with diagnosis and treatment of a vascular anomaly. This preparation minimizes anxiety and helps patients to be more informed about their treatment. Walking a patient through the experience in advance assists the patient to adjust expectations and to plan and implement coping skills to address difficult parts of their experience.

Psychological preparation should take into account the patient's developmental level, cognitive level, and past history with medical procedures. A "walk-through" with the patient should include the anticipated:

- Sensory experience (what will it feel like, look like, smell like, sound like, taste like; body experience)
- Sequence of events (what will happen and in what order)
- Timing and duration (how and when events will occur and how long each part will take)

# Experience with the medical community

Patients often have frustrations with the medical system stemming from misdiagnosis, mistrust of professionals, dismissive attitudes, lack of availability, feeling marginalized, lack of explanation regarding risks and outcomes as well as information regarding condition and treatment, the prognosis of their condition and the complexity of the system they must navigate. They may mistrust professionals or feel marginalized. Navigating the complexity of the system, issues of access, and lack of information regarding their conditions and treatments may also contribute to patient frustration. Because they are sometimes the only people who "get it" and understand the condition, physicians and medical personnel are very important validators for the patient.

Patients often feel anxiety and fear regarding their uncertain futures, and especially about the unknown outcomes of their treatment decisions. In order to endure the demands of their conditions, including their treatments and appointments, patients must maintain their stamina.

# What can care providers do?

Allowing patients to talk about their conditions supports a positive attitude important to both psychological and medical interventions. Patients must be allowed to identify questions, fears, and concerns regarding their conditions. Questions allow patients to honestly express the more negative aspects of their conditions. Very few people understand vascular anomalies, so patients sometimes experience a low sense of validation and support, as well as a high sense of isolation.

Patients frequently ask:

- Will my particular condition create a different experience rather than a "typical" experience?
- What is the impact of my condition on social situations?
- Will my condition lead to restrictions of my daily activities?

Providers can also refer the parents/patients to a social worker or other mental health provider for assessment and management.

# Developmental impact

In order to understand patients with vascular anomalies, the developmental approach views patients through Erikson's psychosocial theory. Erikson suggests that different ages cope with differing developmental challenges:

- Infancy (trust vs mistrust)/ toddlerhood (autonomy vs shame and doubt)
- Childhood (initiative vs guilt) (industry vs inferiority)
- Adolescence (identity vs role confusion)
- Young adulthood (intimacy vs isolation; generativity vs stagnation)

Developmental questions to consider are:

- How does the condition impact their life at present? (identity, intimacy and relationships, employment)
- How has the condition impacted or disrupted normative developmental experience? How has the condition created an experience that differs from the experiences of their peers?

# Therapeutic activities

Therapeutic activities are activities undertaken to reduce stress and isolation. Some of these might include:

- **Writing and journaling:** Patients may use a journal to chronicle their day-to-day experiences. Prompts (such as *What would you like to tell other people about having a birthmark?* ) can empower patients and facilitate disclosure of emotions and feelings about their experience. Writing is one strategy through which a patient can also demonstrate their understanding
- **Bibliotherapy/cinema therapy:** Movies and books that explore themes of difference, individuality, deeper sources of identity (but not necessarily in the same domain of difference)
- **Expressive & creative activities are especially effective for younger patients.** Pretend play, medical play, art, music, movement, writing, sports, blogging, making videos, drama, cooking, building things
- **Empowering, nurturing activities:** gardening, pets, volunteerism, activismAssessing parents stress levels: this may be accomplished with the HRQ or the IES or other such assessment instruments. This assessment should be conducted by a qualified mental health provider.
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Strategies may be provided to families through support staff such as a nurse, physician extender, social worker, child life specialist, or psychologist in conjunction with appointments and procedures. Similarly, information and content can be accessed online or as print material and can be provided for families.

# Emotional fluency and a sense of control

Physicians and therapists can support parents/ patients' mental health by helping them understand, identify, and label emotions and learn the differences between them.

Finding a healthy outlet for emotions is an important component of psychological health, but some parents/patients need assistance in identifying appropriate activities that can transform the energy of an emotion into something constructive and lead to a patient's greater sense of control. Parents/patients should be encouraged to embrace a sense of their own power to create positive experiences. By pairing coping strategies to specific issues, a patient's increased sense of control, mastery, and appropriate engagement will be supported.

## Recommendations for parents/patients

- Access to good diagnosis-specific information, literature, and materials
- VBF website, and other diagnosis-specific portals
- Support groups
- Conferences
- Online groups (diagnosis specific but also larger things like populations living with visible differences)
- Referral to mental health professionals
- Access to supports in workplace, school, community settings
- Pursuit of therapeutic activities

## Coping strategies

Coping strategies are effective ways of dealing with stress. Patients dealing with vascular anomalies are diverse, as are the many ways in which they deal with their emotions.

Positive or progressive strategies may include:

- Aggressive activities – rough and tough play, sports, things that allow for appropriate physical release
- Behavioral avoidance – not going places/doing things that are stressful
- Behavioral distraction – using action or activity to change focus – start talking, walk away, sing song to yourself, tap your foot
- Cognitive avoidance – not thinking about it, ignoring the problem
- Cognitive distraction – using mental tools, thinking about something else (a favorite place, favorite song)
- Stressor modification – identify the cause of stress/ remove/change)
- Cognitive problem solving – planning ways to respond, preparing for situations
- Cognitive restructuring – changing how you think about the problem, reframing
- Emotional expression – therapeutic outlets, expressive activities, appropriate “venting”
- Endurance – “I got through that”; acknowledging personal strengths and investment
- Information seeking – learning about condition, treatments, and research; stay involved medical community
- Isolating activities – separate self – spend a few hours clearing my head and refocusing
- Self-controlling activities – “take a deep breath and count to 10 before responding”; tools for diffusing initial emotional reaction, relaxation
- Social support – talking with others, play, relationships, mentors, social activities, group activities
- Spiritual support – faith, meditation, understanding of life, sense of purpose, acceptance

Regressive/negative coping can include:

- Fighting
- Irrational fears
- Anxiety
- Depression
- Controlling behaviors
- Poor school performance
- Denial
- Regression
- Withdrawal
- Self- injurious behavior

In Summary:
The psychosocial impact for a parent of having a child with a vascular anomaly, or for the adult living with one, can never be underestimated or overlooked. While physicians are trained to treat the “medical” component of disease, the psychosocial component should never be overlooked. It has been demonstrated that for the parents of a child with a vascular anomaly, the diagnosis and treatment process, in and of itself, can be traumatic. For the adult patient, it can cause acute stress and depression. Any parent/patient dealing with a facial vascular anomaly, or otherwise disfiguring lesion, should be referred by the treating physician for an assessment by a trained mental health specialist/social worker to evaluate for acute stress or other implications associated with this condition.

Every patient deserves the right to look normal, and every parent deserves that for their child. Both parents and patients deserve knowledge of all treatment options and the appropriate corresponding psychosocial support from the medical community.

# Course 16: Lesson Quiz

1. Prior to treatment, it is beneficial to provide patients with
   - A. Psychological preparation for the specific procedure.
   - B. Access to literature.
   - C. A referral to social work.
   - D. A thorough psychological evaluation.

2. Psychological preparation includes discussing with patients ahead of time
   - A. Concerns, process, and outcomes
   - B. Sensory experience, sequence of events, timing, and duration
   - C. Therapeutic activities and social support
   - D. Patient’s social background, history, and expectations

3. The Impact of Events Scale (IES) is an instrument that can be used to assess
   - A. Society's impression of an individual living with a vascular anomaly.
   - B. If the diagnosis of a vascular anomaly is a stressful event.
   - C. The level of maternal bonding between the mother and her infant that has been diagnosed with a vascular anomaly.
   - D. The outcome of the treatment of a vascular anomaly.

4. Which is a recommended therapeutic activity for patients?
   - A. Child care services
   - B. Insurance appeals
   - C. Reviewing treatment protocols
   - D. Writing and journaling

5. Which is an example of cognitive distraction?
   - A. Imagining a favorite place
   - B. Going for a run
   - C. Talking with a counselor
   - D. Avoiding stressful places

6. The Hemangioma Reaction Questionnaire (HRQ) is based on which hypothesis?
   - A. Infants diagnosed with a hemangioma will eventually develop symptoms of PTSD.
   - B. Mothers of infants diagnosed with a hemangioma require psychological counseling.
   - C. Stress and PTSD symptoms are never experienced by mothers of infants diagnosed with a hemangioma.
   - D. The diagnosis of an infant with a hemangioma is a stressful or traumatic event.

7. It is important to view a patient’s experience through which framework?
   - A. Expressive
   - B. Socio-economic
   - C. Developmental
   - D. Ontological

8. Which is a common issue for patients with vascular anomalies in dealing with the medical establishment?

A. Medical mentoring
B. Becoming too attached to doctors
C. Misdiagnosis and mistrust
D. Strong sense of competency

9. Living with a visible difference increases the patient experience with:

A. Expression, anger, and social encounters
B. Staring, comments, questions, and social avoidance
C. Social networks, community systems, and caregivers
D. Creativity, humor, and therapeutic expression

10. Patients often feel ambivalence or conflicted pursuing treatment:

A. As they want to avoid trauma
B. Because they need more attention
C. Because they feel concerned pursuing treatment mean they aren’t “ok” with themselves as is
D. Because they are paralyzed by stress

# AUTHOR
## PROFILES

**Linda Rozell-Shannon, PhD, President/Founder**

Dr. Linda is the President and Founder of the Vascular Birthmarks Foundation (VBF). She founded VBF because her own daughter, Christine, was born in 1994, with a hemangioma. She became a medical nomad wandering from doctor to doctor, state to state, to find answers. That was when Dr. Linda realized that there was a void that needed to be filled. In addition to founding VBF, she also pursued a PhD in Education with a dissertation that focused on the stress mothers experience from having a child with a facial hemangioma. She completed her PhD in 2008. She has co-authored two books on the subject, numerous medical journals, and chapters in medical textbooks. She also established the VBF iTeam (an international team of experts that she assembles to travel around the world and educate physicians regarding the diagnosis and treatment of vascular anomalies). In 2015 she pursued a grant to assemble the leading team of experts regarding vascular anomalies together to create the first ever comprehensive on-line course in vascular anomalies. This module is one component of the course you know as “A Foundation in Vascular Anomalies.”

**Leslie M.W. Graff, MS, CCLS**
Psychosocial and Developmental Expert
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Leslie Graff holds a masters degree in Human Development from Brigham Young University. She completed her Child Life training at Johns Hopkins and has worked as Child Life Specialist at UCSF. She has taught at BYU and Ohlone College. She has written undergraduate curricula in Child Life. Leslie been involved with international medical missions and education for more than 15 years. She is on the expert panel of the Vascular Birthmarks Foundation and serves as its Psychosocial and Developmental Expert.

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# Course 16: Lesson Quiz Answer Key

1. A
2. B
3. B
4. D
5. A
6. D
7. C
8. C
9. B
10. C