HEALTH AND RESEARCH AMBASSADOR (HARA) PROGRAM

An advocacy program seeking to engage, inspire, and equip a new cadre of patient stakeholders
WHO ARE WE?

- HARA participants are individuals living with alopecia areata
- Background in research, medicine or psychology (such as graduate students in these fields)
- Work with local mental health professional and experienced dermatologist
- Educate students and physicians at regional medical institutions about the importance of addressing mental health issues
WHO ARE YOU?

- What do you think of when you hear “mental health in dermatology?”
- How would you describe your role?
- Clinical experiences?
WHAT WE ARE NOT TALKING ABOUT...

Trichotillomania
SO WHAT ARE WE TALKING ABOUT?!?

- Ted Talk: “Why We All Need to Practice Emotional First Aid” by Guy Winch, PhD
  - [http://www.ted.com/talks/guy_winch_the_case_for_emotional_hygiene?language=en#t-191810](http://www.ted.com/talks/guy_winch_the_case_for_emotional_hygiene?language=en#t-191810)
  - [https://youtu.be/F2hc2FLOdhI?t=1m21s](https://youtu.be/F2hc2FLOdhI?t=1m21s)
OBJECTIVES

- Understand relationship
- Review prevalence
- Identify and Respond
- Discuss resources
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WHAT IS MENTAL HEALTH?

National Institute of Health (NIH):

- “Mental health includes our emotional, psychological, and social well-being. It affects how we think, feel and act as we cope with life. It also helps determine how we handle stress, relate to others, and make choices. Mental health is important at every stage of life, from childhood and adolescence through adulthood. Mental illnesses are serious disorders which can affect your thinking, mood, and behavior.”
RELATIONSHIP

Mental Health

Physical Health
HOW CAN YOUR PSYCHOLOGICAL STATE AFFECT OUR THINKING?

Let’s See What Dr. Winch Has to Say...

https://youtu.be/F2hc2FLOdhI?t=10m59s
DOESN’T EVERYONE DEAL WITH THIS?

What does this have to do with my dermatology patients?
QUOTES

“I feel like less of a female.”

“It takes effort everyday to maintain happiness.”

“I have a constant feeling of being different.”

“This condition has dictated who I am and is on my mind.”

“Being in the public eye is frustrating.”

“Others assume I am really sick so people avoid me…this is very destructive to a person’s self worth.”

“I feel numb.”

“I feel ostracized and made to feel something is wrong with me.”
SKIN AND THE MIND

“Skin, as a tangible and visible part of the body, can have a magnificent effect on psychological status which is continuously involved in socialization processes from childhood to adulthood.”

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DERMATOLOGICAL CONDITIONS ASSOCIATED WITH MENTAL HEALTH DISEASE

- Alopecia areata
- Acne
- Atopic dermatitis (eczema)
- Hemangiomas
- Icthyosis
- Kaposi’s sarcoma
- Psoriasis
- Rosacea
- Seborrheic dermatitis
- Vitiligo
PSORIASIS

Cross-Sectional Design

Key Findings:

- Low QOL (similar to CHF and cancer): shame, low self-esteem, isolation from social interaction
- Clinician assessment of symptom severity is less predictive of well being than patient perceived symptom severity
- Poor baseline QOL may adversely affect treatment success

Breuer K et al. J Eur Acad Dermatol Venereol. 2015
VITILIGO

INVESTIGATIVE REPORT

Stigmatisation, Avoidance Behaviour and Difficulties in Coping are Common Among Adult Patients with Vitiligo

Krüger C. Acta Derm Venereol. 2015

Cross-Sectional Cohort Study

Key Findings:

- High prevalence of stigmatization
- Worse QOL than controls
- Elevation in social anxiety, avoidance, helplessness, and anxious-depressive mood

Fig. 1. Comparison of the main questionnaires’ scores between patients (n = 90) and controls (n = 23). Patients with vitiligo scored much higher in the Dermatology Life Quality Index (DLQI) and the Adjustment to Chronic Skin Disorders Questionnaire sub-scales Social Anxiety/Avoidance, Helplessness and Anxious-Depressive Mood. The significance was weak in the subscales non-specific to skin diseases (Anxious-Depressive Mood). There was no difference measurable between patients and controls in the Beck Depression Inventory (BDI). Significance levels were determined by a t-test. p-values were 0.003 (DLQI), < 0.001 (Social Anxiety/Avoidance and Helplessness), 0.015 (Anxious-Depressive Mood) and 0.775 (BDI).

Grouped scores revealed that the vast majority is not affected by vitiligo.
Hidden Victims of Childhood Vitiligo: Impact on Parents’ Mental Health and Quality of Life

Abdulrahman A. A. AMER\textsuperscript{1}, Uwesu O. MCHEPANGE\textsuperscript{2}, Xing-Hua GAO\textsuperscript{1}, Yuxiao HONG\textsuperscript{1}, Ruiqun QI\textsuperscript{1}, Yan WU\textsuperscript{1}, Yunfei CAI\textsuperscript{1}, Jinlong ZHAI\textsuperscript{1} and Hong-Duo CHEN\textsuperscript{1}

Abdulrahman, A. et al., Acta Dermato-Venerology. 2014

Cross-Sectional Design

Key Findings:

- Parents of children with vitiligo have a poorer QOL and significantly more psychological stress than parents of healthy children
- Mothers more adversely affected than Fathers
- Parents of affected children “need as much care and attention as their affected children”
The psychological impact of rosacea and the influence of current management options

Farah Moustafa, BS, Robin S. Lewallen, MD, and Steven R. Feldman, MD, PhD

Moustafa, F. et al., J Amer Acad Derm. 2014

Systematic Review

Key Findings:

- Rosacea negatively impacts QOL and patients with rosacea are more likely to experience depression, embarrassment, social phobia, stress, and higher subjective disease perception.

- “By acknowledging the psychosocial burden of rosacea, physicians can more comprehensively treat patients and work towards better outcomes”

- Consider multifaceted approach to treatment that focuses on the patients' concerns regarding their rosacea
ATOPIC DERMATITIS

The Burden of Atopic Dermatitis: Impact on the Patient, Family, and Society

Christie L. Carroll, M.D.,* Rajesh Balkrishnan, Ph.D.,*‡ Steven R. Feldman, M.D., Ph.D.,*† Alan B. Fleischer Jr., M.D.,* and Janeen C. Manuel, Ph.D.*†

Carroll, C et al. Ped Derm. 2005

Systematic Review

Key Findings:

- Often/always frustrated, embarrassed and angry by appearance, overprotected/undisciplined as children, increased incidence of psychiatric disorder as adults
- Lower social functioning, mental health scores than those with DM and HTN
- Children increased dependency, fearfulness, sleep disturbance; interference with intellectual development, limitation on sports participation and peer/teacher relationship
ALOPECIA AREATA

Research Article

Prevalence of Psychological Disorders in Patients with Alopecia Areata in Comparison with Normal Subjects

Shahin Aghaei,¹ Nasrin Saki,¹,² Ehsan Daneshmand,² and Bahare Kardeh²

Aghaei, S. J Int Sch Research Not, 2014

Case Control Study

Key Findings:

- Significant diff in prevalence of depression (P = 0.008), anxiety (P=0.003), neuroticism (P=0.045)
- Social, familial and uncontrollable problems influence these patients more so than the general population (coping)
- Social support= protective factor for mental and physical health
ALOPECIA AREATA

INVESTIGATIVE REPORT

Psychological Status of Patients with Alopecia Areata

Stefania ALFANI¹, Valeria ANTINONE², Aurelia MOZZETTA², Cristina DI PIETRO¹, Cinzia MAZZANTI³, Piero STELLA³, Desanka RASKOVICH⁴ and Damiano ABENI¹

Alfani, S. Acta Derm Ven, 2012

Cross Sectional Study

Key Findings:

- Depression, anxiety, family relationships, hysteria, hypochondriac tendencies, and conflict with social environment more common in AA patients than matched controls
- Increased health concerns → frequent, abnormal health worries, feeling more unwell than general population → unnecessary clinic visits/emails/calls, increased spending and time
WHY SHOULD WE BE CONCERNED?

Mental health negatively affects

- Quality of life (QOL)
- View of self and relationships with others
- Derm disease
- Management of dermat disease

ACGME: advocacy, quality of care, interprofessionalism

Data that chronic disease in children have long term negative impact on future health outcomes
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WHAT CAN WE DO?

- Recognize all psychologically unstable patients?
- Diagnose psychiatric diseases?
- Treat mental health diseases?
WHAT CAN WE DO?

- Recognize signs
  - Changes in mood: sad, tense, worried
  - Changes in behavior: adherence to treatment / appointments, substance use, sleep, etc.
  - Changes in relationships: disinterested, uninvolved
  - Other: difficulty concentrating, unexplained wt loss, unexplained physical symptoms (HA, stomach aches)

- Ask and Listen ( = screening)
- Know how to respond
I NEED 1 VOLUNTEER 😊

- Let’s see how realistic this is within 5 mins

- Goal: Quickly assess a part of your patient’s skin disease experience + find effective ways to connect your patient to support
It is the end of a really busy day in clinic and you are a bit behind schedule. You had a full load of patients. Your last patient is someone you know very well so you expect the visit to be quick. However, just as you are wrapping up the visit something makes you worried that he/she is not doing well. You remember this lecture and even though your time is tight, you decide to ask how your patient has been doing emotionally.
TAKE HOME POINTS

- Recognize signs
  - Changes
    - mood
    - behavior
    - relationships
    - unexplained physical symptoms
- Ask, listen, and consider brief questionnaire
- Know how to respond
- Emergencies
BARRIERS?

- Physician
- Patient
- System
HOW DO WE KNOW SCREENING HELPS?

Cross Sectional Study

Key Findings:

- Good test performance characteristics: Sensitivity (87%) and NPV (84%)
- Easy, quick, well accepted, simple scoring
- Routine use screening questionnaire may help increase recognition of psychiatric disorders in dermatological patients

Picardi, A. J Psych Research, 2004

http://www.gl-assessment.co.uk/products/general-health-questionnaire/faqs?css=1
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RESOURCES

- What resources are already available at your medical campus regarding support?
WHAT RESOURCES ARE AVAILABLE?

- Online
- Phone
- In person
  - Group
  - Referral
REFERRAL

- Strategies for meaningful referral
  - Working relationship with mental health specialist
  - Awareness mind-body interaction
  - Patient education (stress blame)
National Alopecia Areata Foundation (NAAF)

History

- Resource for over 30 years

Mission:

- Support: patients and medical providers
- Research: funding, clinical trials
- Education: advocacy, awareness
SUPPORT

- The Need
- Personal Story
- What NAAF Provides
CONFERENCES
SUPPORT GROUPS
EVENTS

[Image of a group of children smiling and posing together]

[Image of three young girls holding a sign that reads "National Alopecia Areata Foundation"]
EDUCATION

- Patients self-advocacy
- Public awareness

Original article

An Evaluation of a Positive Youth Development Program for Adolescents with Chronic Illness

Gary Maslow, M.D., M.P.H.*, Cathleen Adams, M.D., Matthew Willis, M.D., M.P.H., Jodie Neukirch, M.S., Kate Herts, M.S., Wendy Froehlich, M.D., Diane Calleson, Ph.D., and Michelle Rickerby, M.D.
Miya Mathur

Hi Friend, My name is Miya and I’m excited to be in Kindergarten! I was born on January 21, 2009. My favorite colors are pink, purple, blue, red, silver and golden. I like swimming and ballet, and I’m also learning to play the violin.

My hair is different because I have Alopecia Areata, an autoimmune condition, which makes my body not like my hair. It’s like being allergic to my hair. It doesn’t make me sick and it isn’t contagious.

I love my family and I love having friends. I wish to learn more about you.

For more information about Alopecia Areata, visit www.naaf.org
OTHER SUPPORT WEBSITES

- **ECZEMA**: National Eczema Association

- **PSORIASIS**: National Psoriasis Foundation
  [https://www.psoriasis.org/](https://www.psoriasis.org/)

- **ROSACEA**: National Rosacea Society
IN SUMMARY...

- Understand relationship between physical health and emotional health
- Be aware of increased prevalence of mental health issues in dermatologic populations
- Enhance ability to identify and respond to emotional distress
- Feel comfortable discussing available supportive resources with your patients
REFERENCES

- Available upon request