Psychosocial Implications of Patients with Hemophilia and Inhibitors

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A Day in the Life:

- Life with Kids
Definition of Inhibitor/Patient

- What is an inhibitor?
  - Inhibitor is a rare complication where the immune system creates antibodies to the infused clotting factor because it views the factor as a foreign substance that needs to be destroyed. Antibodies then get rid of the factor before it can stop bleeding/protect the patient.
  - Usually occurs between 5-50 clotting factor exposures
  - Severe Hemophilia patients have higher incidence to develop an inhibitor, but mild/moderate patients also have a 5-8% chance.
- Emory/CHOA has 54 active inhibitor patients.
Impact of Current Recommended Treatment

- Frequency
- Volume
- Bypassing agents
- B Cell & T Cell Suppression
- Peripheral access vs central venous access
- Dosing a bleed
- Frequent visits to HTC plus lab draws
Implications of Inhibitors

- Bleeding regardless of adherence
- Re-bleeding & target joints
- Frequent hospitalizations
- Venus access malfunction
- Expensive
- Limited ability to independently participate in activities of daily living
- Treatment fatigue
Physical Implications

- Child’s connection to the physical self and how is influenced
- Frequency number of re-bleeds into a joint
- Pain
- Hospitalizations
- Stigmatizing- DME required for “normal” movement
- Permanent joint damage- aging child before time
- Venus Access Devices and complications
Economic Implications

- Loss of work time (Parent)
- Disruption of family norms, need for extra expenses
- Expensive
  - Families require multiple third party support to cover cost (PSI, Katie Beckett Medicaid, copay assistance)
  - Insurance making it more difficult to obtain medication necessary (PA)
Developmental Implications

- Limited ability to independently participate in activities of daily living - developmentally disruptive
- Enmeshment/Overprotection
- Identification as “disabled”
Social Implications

- Stigma as “sick”
- Treated differently by others vs. inability for others to understand as he “looks normal”
- Loss of school time
- Inability for kid to participate in “normal” childhood activities (sports, bounce houses, ball pits...)
Emotional Implications

- **Learned Helplessness** may occur because of bleeding regardless of treatment efforts
- Caregiver distress of balancing responsibilities
- Disruption of family life
- Role of guilt
- Escalator
Treatment Fatigue

- Difficulty to adhere to complicated treatment regimen
- In chronic disease, adherence decreases as the complexity of the medication regimen increases (i.e. infusing FEIBA and Alphanate at different times of day; length of time to push medications; adding Rituximab, etc.)
- To combat treatment fatigue, WHO argues providers must address patient psychosocial factors and strengthen the relationship between provider and patient.
The “So What?”

- When treating a patient with an inhibitor, it is important that Medical Professionals solidify the patient/provider experience by maintaining empathy for the patient/family.

- Furthermore, recognizing that patients and caregivers might be grieving as they cope with the inhibitor could be helpful.

- Remember:
  - Inhibitors limit the ability for kid to be a kid.
  - Inhibitors impact the daily lives of all caregivers.
  - Inhibitors can create extreme financial strain on the family.
  - Inhibitors can affect the quality of life for patients and caregivers.
Coping Experiences of Mothers of Children with Hemophilia

- **Shared experiences at time of diagnosis:**
  - Feeling of sadness (almost to suicidal ideation)
  - A sense of being accused – Dad would have had a normal child except for me
  - Neglect of other Child
  - I have caused extra expense and need to prevent child from requiring extra infusions
  - Inability of being able to protect child from suffering - Infusion time or poor response to factor when bleeding
  - Overwhelmed by fear and worries for child’s safety and well being – having to live in the hospital and not sleeping due to fear

- **A second phase- the turning point:**
  - All hinged on having increased knowledge and skills such as doing home infusion
  - Having an outreach or support person(s) or team to share the burden

- **Third phase was reconciliation with how life changed:**
  - Claiming new security as they could deal with daily situations and make knowledgeable decisions
  - Adapting professional life to be with son and returning to work (if able) was not a failure as a professional but may present a different timeframe
  - Growth from the experience and learning own strengths
  - Being hopeful as treatment for hemophilia is very different now and is continuing to change

Grief and Coping

- Grief models can be applied to the acceptance process of the new bleeding disorder diagnosis.
Strategies

- Provide empathy
- Consider caregiver coping and capability when prescribing ITI
- Encourage a “new normal” while recognizing the family may be grieving
- Always maintain a strengths perspective
- Provide education for self sufficiency and empowerment
- Encourage psychosocial support
Words of Encouragement