



Adherence: A Physician Perspective

Marcus E. Carr, Jr., M.D., Ph.D.
National Hemophilia Foundation
Annual Meeting
November 2001



Barriers to Adherence

- Time constraints
 - Managed care--reimbursement based on “complexity of visit”, not patient/family issues
 - Academic pressure



Barriers to Adherence

- Complexity of Multidisciplinary Recommendations
 - vying for priorities
 - increasing confusion



Barriers to Adherence

- Size of medical team: effect on rapport development
 - hematology/oncology service
 - teaching institutions
 - coordination with other large teams (ID/hepatology/orthopedics)



Strengths of HTC/Hemophilia Community related to Adherence

- Support systems
 - chapter/center educational programs
 - formal and informal networks
 - clinical staff
 - home infusion companies



Strengths of HTC/Hemophilia Community related to Adherence

- Chronic Nature of the disease
 - many opportunities for follow/up; rapport development



Strengths of HTC/Hemophilia Community related to Adherence

- Familiarity of treatment setting
 - “home” therapy
 - semiannual/annual visits to same center
 - links to home infusion provider



Strategies to Support Adherence

- Broaden and support the understanding of patient/family
- Increase access to health care providers
 - toll-free telephone number
 - use of core team--COMMUNICATION!
 - coordination/triage/continuity of care
 - direct access (privacy)



Strategies to Support Adherence

- Enhance empathy of team
 - rapport development
 - improving quality time with patient
 - preclinic reviews
 - initial interview with RN/SW
 - division of labor (ex: risk reduction)
 - HTC core staff as hem/onc resource



Strategies to Support Adherence

- Add external cues
 - clinic follow-up letters
 - plans of care developed with patient
- Increase support systems
 - education through chapter and clinic programs (ex: hepatology, prophylaxis)
 - newsletters
 - lunch time networking with families



Strategies to Support Adherence

- Increase simplicity of treatment plans
- Prioritize health care treatment needs if possible
- Celebrate humor
- Be able to set boundaries when needed
- Communicate with patients on a level of commonality, trust and understanding



Case Study 1

Pain

Narcotic Medications

Accelerating Usage

Substance Abuse

Medical Non-Compliance



Case Study 1 - The Patient

- 35 year old male with severe FVIII, HCV and HIV positivity, hemophilic arthropathy
- Chronic use of pain medications
- Does not like to use “too much” factor for bleeds
- Fear of viral transmission



Case Study 1 - Areas of Concern

- Non-compliance in treating bleeds with enough factor replacement
- Refusal to try other options for adjunctive pain management
- History of substance abuse/depression



Strategies in Substance Abuse Related Non-Compliance

- Communicate honesty with patient about the problem/your legal and ethical responsibility to patient
- Suggestions for evaluation and treatment of addiction
- Set boundaries and explain consequences with patient as to how you can follow him/her
- Document the problem in letter and chart form



Case Study 2

A Case of Physician “Perceived” Patient Non-Compliance



Case Study 2 - The Patient

- 28yo with severe FVIII, severe joint arthropathy, HCV
- Difficulty maintaining employment due to multiple bleeds-concerned about livelihood, caring for family
- Acute ankle and elbow pain (difficulty in ambulating)
- Has been evaluated by hepatology who wants to do a liver biopsy



Perceived Non-compliance

- Hepatology wants to pursue liver biopsy
- Patient position - I cannot cope with liver biopsy now. I can barely walk.
- Seeing orthopedics who offers surgical intervention for pain relief
- New Transient inhibitor development-using NovoSeven and FEIBA



Case Study 2 - Perceived Non-Compliance

- Patient wants to delay liver biopsy, hematologist listens and supports patient
- hepatology disagrees, no active evidence of liver disease (negotiate an ultrasound)



Strategies with Perceived Non-Compliance

- Listen to patient identified acute problem
- Prioritize/partialize treatment needs if possible
- Work together through communication with patient and other specialists involved in care (conference, phone call, letter)



**The Complex Interplay
of Medical, Ethical and Legal
Questions Surrounding the Care
of HIV Positive Patients and
Their Families Adds A New
Layer of Complexity**



Tough Questions:

- What are the appropriate steps with a 30 year old male patient who is HIV positive, rarely comes to clinic and now has an unmarried, pregnant partner who has never been HIV tested?
- What do you do when there is already one child (untested), and the partner is 9 months pregnant with a second child?



Areas of Non-Adherence

- Failure to Disclose HIV status to partner
- Requests testing and then repeatedly fails to come to clinic
- Virginia law requires partner notification and offspring



Strategies to Increase Compliance

- Be sure of Legal Status - Consult the Virginia Department of Health re: Virginia law with case scenario
- Utilize staff to provide consistent outreach to patient and partner for testing
- Write a letter explaining your legal and medical obligations to partner and children
- Utilize sensitivity in the fear involved in the situation for the patient, partner



Summary

- Remember that each Patient and each Situation is unique
- Attempt to identify the root cause of the non-compliance - fear, anger, lack of knowledge
- Emphasize that the goal is the best care for the patient and his family
- Take the time to COMMUNICATE, COMMUNICATE, COMMUNICATE.....