

Experienced RN Coordination of Pediatric Sickle Cell Patients in the Office and Outpatient Clinic Setting: A Comprehensive, Pro-Active Nursing Model



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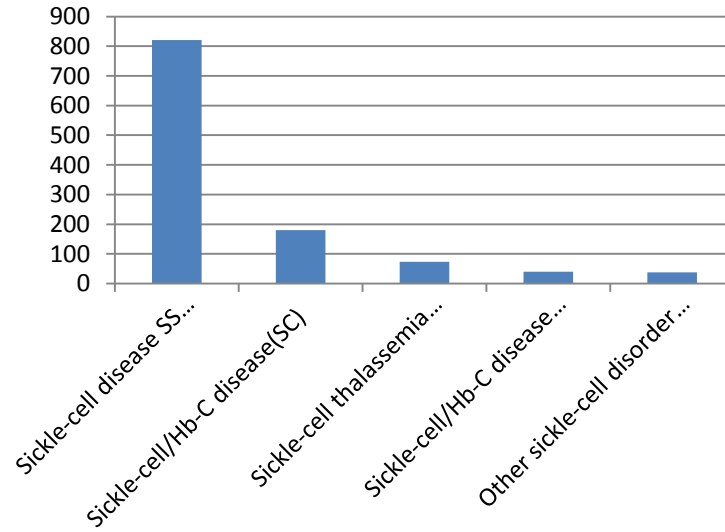
Sickle Cell Program of Children's National Health System



- Approximately 1400 patients age 0-21 years old
- One of the largest pediatric sickle cell programs in the US
- Multidisciplinary staff: physicians, nurse practitioners, nurse coordinators, social workers, genetic counselor, psychologists, and research assistants
- Located in a diverse, urban setting in the nation's capitol



Sickle Cell Program of Children's Cont'd



Clinic Structure of Sickle Cell Program



- Sixteen to seventeen clinics are held each week
- Follow-up clinics with individual providers (NPs and MDs) held 4 days a week
- Specialty clinics are held 2-3 times per week
- Sick visits triaged by nurse coordinator and are seen by nurse practitioner on a daily basis as needed



Specialty Clinics/Programs



Transition Clinic-18-21 year olds

Infant Clinic 0-2 year olds

Transfusion Program

Hydroxyurea Education Clinic

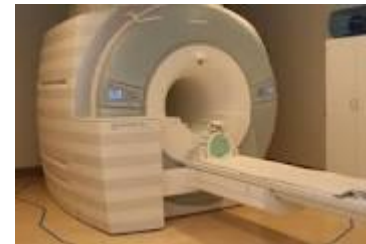
Medical Surveillance

- Yearly transcranial doppler (TCD) screenings



- Lab monitoring for Hydroxyurea therapy and routine sickle cell care

- MRI/MRA/Ferriscan screenings



- Transfusion related lab monitoring



Medical Surveillance Cont'd



- Monitoring for vaccines specific to sickle cell disease (SCD)



- Regular follow-up visits: every 6 months routine sickle cell; every 2-3 months HU maintenance and every 3 months infants
- Yearly ophthalmology and audiology examinations (for patients on chelation therapy)



Compliance and Access Issues for High Volume Clinic



- Access to medical staff for routine patient questions
- Appropriate identification of complex questions and accessibility of high level response
- Obtain and medically support authorizations for medications



Compliance and Access Issues Cont'd



- Coordination of surgical procedures



- Refilling routine medications
- Access to infusion appointments for blood transfusions
- Compliance with routine recommended follow-up and transfusion appointments



Literature on Care Coordination



A quality improvement project by Vessy and colleagues showed that “nursing care coordination improved the quality of patient care through providing clinical management and patient education, streamlining service provision, and helping eliminate unneeded care”.

JA Vessy, et al, Journal of Pediatric Nursing, 2015



Question to be Addressed

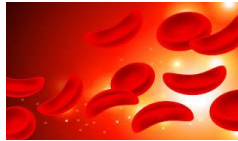


What kind of nursing coordination model will increase patient access to care and compliance with recommended treatment plans in a high volume, pediatric sickle cell clinic?

Comprehensive Pro-active Nursing Model



Experienced RNs with extensive knowledge of sickle cell were identified and use the following skills to address compliance and access issues:



- Ability to answer routine questions and issues independently
- Ability to recognize issues requiring higher level of intervention

Comprehensive Pro-active Nursing Model



- Ability to fill routine prescriptions with agreed upon guidelines



- Pro-active preparation of all clinics, anticipating and preparing for needs such as TCDs and vaccinations

Clinic Participation



Participation and presence in clinics are a crucial part of both comprehensive and pro-active nursing.

Coordinators become active members of the team and participate in care decisions.



Follow-up plans can be made in real time when possible.

Clinic Participation Cont'd



Relationships with families can be established and grows with each visit.



Trust grows and families become more comfortable opening dialogues that can enhance care and outcomes.

Clinic Participation Cont'd



Families will have a name to a face and will be more comfortable when phone interactions are needed.



Issues unique to certain families will be known not only by the provider but the coordinator.

Education

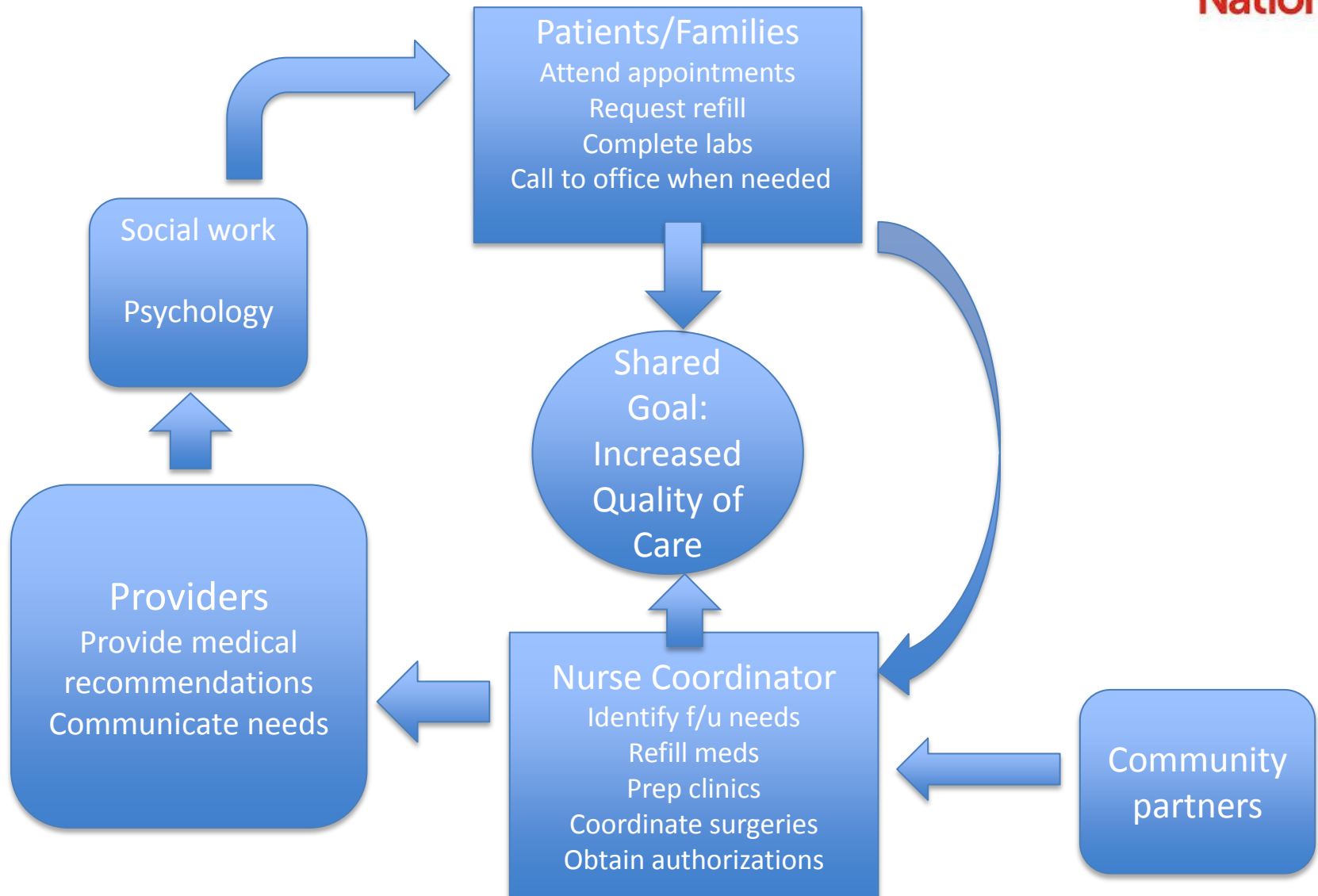


- Another advantage to participation in clinic visits is the opportunity to provide brief education.



- Age appropriate educational material is handed out during clinic visits.

Coordinator Relationships



Conclusion

A pro-active, comprehensive approach to a high volume sickle cell clinic at Children's National has improved patient care and increased satisfaction for both patients and families.

Further research is needed to fully understand the impact of care coordination.

