

Developing a Newborn Screening Social Work Model of Care: An Opportunity for Early Psychosocial Intervention

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A Place for Psychosocial Intervention in NBS

“ Newborn screening is more than testing. It is a coordinated and comprehensive system consisting of education, screening, follow-up, diagnosis, treatment and management, and program evaluation.”

MCHB. Newborn screening: toward a uniform screening panel and system. Executive summary. Electronic citation 2005;available from: URL: <http://www.mchb.hrsa.gov/screening/>.

“Good medical care is vital, but unless the root social causes that undermine people's health are addressed, the opportunity for well being will not be achieved. ”

WHO Commission on the Social Determinants of Health (2006)



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Theoretical Frameworks Applied to Illness-Related Family Stress in the Newborn Period

Attachment Theory

- Medical problems in infancy increase vulnerability to attachment problems between mother and infant (Goldberg, 1988)

Family Systems Theory

- Family is a system and changes/stressors etc. affect the entire system
- Parent adjustment is connected to the infant-parent dyad, family and social constructs of parenting stress, marital quality and social support (Martin and Pianta, 1996)

Social Determinants of Health

- Factors related to how people live/work contribute to health inequities (Labonte and Schrecker, 2007)

Stress and Coping Theory

- Adjustment to threat of illness is best understood in terms of appraisal of the situation (significance of stressor) and subsequent coping (cognitive, behavioural resources to manage demand) (Lazarus, 1993)



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Psychosocial Issues in Newborn Screening

Waiting for Results

- Cognitive uncertainty and emotional distress found higher in parents of infants with abnormal NBS results (Tluczek et al., 2005)

False Positive Results

- Parent sleep disturbance and infant feeding problems (Bodegard, 1983),
- Increased parent stress and infant hospitalizations (Waisbren et al., 2003)
- Imposing restrictions based on carrier status (Hampton, 1974)

Resolving Diagnosis When Baby is Asymptomatic

- Diagnosis comes at a critical, often vulnerable time in parent-infant attachment – influencing parent confidence, conceptualization of child's identity (Grob, 2008)
 - Anticipatory anxiety of pain that child may experience (Rao and Kramer, 1993)

Mixed Evidence re: Diagnosed Clinically vs. by Newborn Screening

- Positive impact on overall parent coping (Waisbren, 2004) vs. psychological distress at similar levels to clinically diagnosed neonates (Cono et al., 1997)



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Newborn Screening Centre at The Hospital for Sick Children

- 1 of 5 Regional Treatment Centres established in Ontario with expanded newborn screening in 2006
- Largest number of screen positive neonates retrieved in the province
- Centralized Model
 - 1 team provides care to all NBS positive infants – retrieval, follow-up and transition to subspecialty teams
- Interdisciplinary Approach
 - 2 RNs, 1 genetic counsellor, 0.6 social worker, 1 information coordinator



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Philosophy of Psychosocial Care - SickKids NBS team

Early Intervention/Prevention

- psychosocial care begins at retrieval
- early support/intervention contributes to improved health for infant and family (aligned with NBS goals)

Coordinated approach to care and treatment

- Key elements of a global strategy for women's and children's health involve comprehensive interventions and services, integrated care across sectors and strengthened health systems.

Global Strategy for Women's and Children's Health, United Nations Secretary General, 2010
http://www.who.int/pmnch/topics/maternal/201009_globalstrategy_wch/en/index.html



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NBS Social Worker – Key Roles

Consultant

- NBS & subspecialty teams around addressing psychosocial issues

Advocate

- Patient/family needs integrated into policy and procedures

Consistent Provider

- Promote smooth transition to subspecialty teams
- Communicate needs, strengths and preferred ways of working to other team members (strong early partnerships)

Assessment /Intervention of Child and Family In Context

- Identifying and addressing vulnerabilities and barriers to adaptive coping and optimal health (particularly postpartum and social circumstances)



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Retrieval and Initial NBS Contact Visit

- Consultation:
 - Barriers to follow-up
 - Unable to locate families
 - Refusal of follow-up
- Assessment:
 - Processing of the NBS results
 - Risk factors – postpartum adjustment, parent mental health, child welfare concerns
 - Supports available
 - Resource needs
- Awaiting Results:
 - Resource Linkage
 - Telephone counselling and support



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Transfer to Subspecialty Follow-Up

- Supporting disclosure of diagnosis
 - Adjustment counselling
- Transition to Subspecialty
 - Strategies for working with family, understanding needs and strengths
 - Consistency in providers builds alliance with family
- Short-Term Case Management
 - Arranging funding, linking with community resources to broaden support network/address other identified risk factors,
- Case Transfer
 - Transfer case to program social worker where there is high level of risk, chronic family stress requiring longer-term intervention



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No Further NBS-Related Follow-Up Required

- Support around residual anxiety related to NBS experience
- Referral to community services and supports for identified needs unrelated to NBS experience



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Case Example

NBS positive result suggestive of sickle cell disease. Single mother, arrived in Canada >5 years as a refugee. No stable support system. Significant financial constraints. Difficulty in engaging mother to bring baby for confirmatory testing at the retrieval stage. At 1st appointment with NBS team, mother able to cognitively grasp information but presented with unusual affect (i.e. elevated mood, despite difficult topic). Social work follows while awaiting test results and through transition to haematology clinic. Mother discloses significant trauma history, difficult experience of baby's NBS results and subsequent diagnosis trigger flashbacks. Noncompliance with clinical follow-up follows.

NBS Social Work Intervention

- support retrieval team members in exploring strategies for bringing family in, problem solving potential barriers
- conducting psychosocial assessment with parent/s (pp coping, reaction to NBS results, identifying main concerns, needs assessment etc)
- interim follow-up with families at higher risk for poor adjustment
- adjustment counseling
- liaising with external resources to support family (child welfare, trauma counselling, public health RN)
- support/collaboration with subspecialty team re: strategies for relationship building with family, understanding factors affecting parent coping with diagnosis
- transfer to program social worker for long-term follow-up



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Feedback/Future Directions

Feedback

- ↑ insight and awareness of issues facing families, can tailor treatment plan
- Predictability and reassurance in times of uncertainty
- Optimizes communication between family and team

Future Directions

- Program evaluation of the centralized NBS model at our Centre
- Qualitative research exploring family experiences with psychosocial care received throughout NBS process



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Thank You!



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