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# Facilitators and Barriers to Neonatal Intensive Care Unit Follow-Up Program Attendance: A Critically Appraised Topic

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Facilitators and Barriers to Neonatal Intensive Care Unit Follow-Up Program Attendance: A

Critically Appraised Topic

May 2017

This evidence project, submitted by

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has been approved and accepted

in partial fulfillment of the requirements for the degree of

Master of Science in Occupational Therapy from the University of Puget Sound.

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Key words: NICU, follow-up, attendance

### **Abstract**

Kari Tanta, PhD, OTR/L, FAOTA is the rehabilitation manager of the neonatal intensive care unit (NICU) and the NICU follow-up (NFU) program at Valley Medical Center (VMC). To address the problem of decreased NFU attendance, the following clinical question was asked: “For families with an infant who has been discharged from a NICU, which factors promote or discourage utilization of follow-up services?” Numerous facilitators and barriers affecting attendance were identified relating to severity of infant illness, parent socioeconomic status and education levels, and pragmatic factors including timing of scheduling.

Knowledge translation activities undertaken included collaboration with University of Washington (UW) students, collaboration with grant writer Leanna Birge, PhD, and submission of findings for publication. Due to conflicting schedules, collaboration with the UW students was limited to a brief telephone dialogue. The collaboration with Dr. Birge will directly support the acquisition of grants for informal quality improvement (QI) studies. The submitted article will potentially reach many readers specializing in pediatrics, though it is difficult to assess the true reach of the article. Further research should investigate effective methods for increasing NFU program service utilization.

### **Executive Summary**

The research process began by meeting with our collaborating clinician, Kari Tanta, PhD, OTR/L, FAOTA, the pediatric manager at Valley Medical Center (VMC), to identify the following clinical question: “For families with an infant who has been discharged from a neonatal intensive care unit (NICU), which factors promote or discourage utilization of follow-up services?” This question arose from the issue that the NICU at VMC is currently facing: poor utilization of NICU follow-up (NFU) program services by consumers. This program consists of appointments scheduled with a multidisciplinary team (including occupational therapy) at specific intervals after discharge from the NICU. Its purpose is to monitor health and developmental progress in infants who are at high risk for health problems and developmental delays. Despite the importance of NFU services and their role in improving health outcomes, consumers often do not attend their scheduled appointments, frequently cancelling appointments without notice. By asking us to investigate the literature to determine what factors influence access to and use of NFU services, Dr. Tanta hoped to identify ways her program can support its consumers in order to increase NFU appointment attendance.

We investigated this question by performing a critically appraised topic (CAT) review. This process included identifying inclusion and exclusion criteria to select appropriate literature sources and then utilizing applicable search terms to conduct a thorough review of the literature in databases including PubMed, Medline, CINAHL, OT Search, Cochrane Library, Proquest, Primo, Psycinfo, Google Scholar, and Nursing and Allied Health Database. Ultimately, we identified 17 articles that met our inclusion and exclusion criteria including three experimental studies, six outcome studies, one qualitative study, five descriptive studies, and two unrated/evaluation papers.

With such a wide variety of methods used to investigate this question across different populations, each study identified unique barriers and facilitators affecting NFU service utilization/attendance in their sample, with some common results. Common factors included amount of support and resources available to families (Ballantyne, Benzies, Rosenbaum, & Lodha, 2014), maternal stress level (Ballantyne, Benzies et al., 2014; Ballantyne, Stevens, Guttman, Willan, & Rosenbaum, 2014), being a single mother (Ballantyne, Stevens et al., 2014; Campbell, Halinda, Carlyle, Fox, Turner, & Chance, 1993), maternal drug use (Ballantyne, Stevens et al., 2014; Campbell et al., 1993; Harmon, Conaway, Sinkin, & Blackman, 2013; Nehra, Visintaner, & Kase, 2009), maternal age (Ballantyne, Stevens et al., 2014; Campbell et al., 1993; Nehra et al., 2009), proximity to service facility (Ballantyne, Stevens et al., 2014; Campbell et al., 1993; Harmon et al., 2013), and parent's perception of their infant's health status (Ballantyne, Benzies et al., 2014; Ballantyne, Stevens et al., 2014; Campbell et al., 1993; Harmon et al., 2013; Tien, Peterson, & Shelley, 2002). A few studies implemented specific methods for increasing attendance and identified the following methods as successful: calling before appointments, eliminating morning appointments, reducing paperwork, scheduling appointments before discharge, and providing transportation to appointments (Catlett, Thompson, Jondrow, & Boshkoff, 1993; Patra, Greene, Perez, Silvestri, 2014).

This knowledge has implications primarily for the providers of NFU services. Identifying the factors associated with under-utilization of follow-up services is the first step in implementing program changes that would increase service utilization. Providers must contemplate how they can compensate for the common barriers that prevent their clients from accessing and/or using services. For any NFU program facing the issue of decreased

attendance, there is benefit in using the literature to determine which factors could be influencing their access to the NFU services for their specific population. To further improve results, providers can survey their clients directly to determine barriers and then share their findings to contribute to the current literature base on this topic.

With these findings, we undertook the following knowledge translation activities: collaborating with University of Washington (UW) occupational therapy students, collaborating with grant writer Leanna Birge, PhD, and submitting findings for publication. Collaboration with the UW students and Dr. Birge did not result in a tangible outcome, but rather consisted of a dialogue aimed at sharing knowledge to further projects related to increasing attendance at the VMC NFU program. The submitted paper has not yet been approved for publication, and thus has not yet produced any outcomes.

### Final CAT Paper

**Focused Question:** For families with an infant who has been discharged from a NICU, which factors promote or discourage utilization of follow-up services?

**Collaborating Occupational Therapy Practitioner:** Kari Tanta, PhD, OTR/L, FAOTA

**Prepared By:** Ciara Clark, Lauren Maher, Mariko Rudy

**Chair:** Jennifer Pitonyak, PhD, OTR/L, SCFES

**Course Mentor:** Renee Watling, PhD, OTR/L, FAOTA

**Clinical Scenario:** A rehabilitation manager of a hospital pediatric unit needs to identify:

1. Which factors promote or discourage attendance at NICU follow-up programs in order to incorporate supports into the program that will increase utilization of follow-up services by families and
2. Supporting evidence to demonstrate the need and efficacy for these frequently threatened programs.

### Review Process

#### Procedures for the selection and appraisal of articles

Inclusion Criteria:

- Peer reviewed journal articles
- Samples of infants and families who have been discharged from NICU
- Samples of healthcare professionals involved with NFU outpatient services
- Involving NFU outpatient services
- Discusses barriers to NFU participation
- Discusses facilitators to NFU participation

Exclusion Criteria:

- Does not address follow-up services
- Service delivery other than outpatient

### Search Strategy

Categories	Key Search Terms
Patient/Client Population	Families, infants, neona*, prematur*

Intervention (Assessment)	NICU, neonatal intensive care unit, developmental  AND  Follow-up, follow-up program, occupational therapy, physical therapy, post-discharge
Comparison	Barriers, facilita*, promote, discourage, encourage, inhibit*
Outcomes	Attendance, adherence, participation, developmental outcomes, quality of life, well-being

<b>Databases and Sites Searched</b>
PubMed, Medline, CINAHL, OT Search, Cochrane library, ProQuest, Primo, Psycinfo, Google Scholar, Nursing and Allied Health Database

***Quality Control/Review Process:***

We started by inputting simple phrases (as shown below) in the major search databases such as Primo and PubMed. From there, we realized that although we were getting results, we needed to widen our scope. Using Google Scholar, we found that this widened our search too much. However, we took a few good articles from this search, not wanting to forgo them, but stopped viewing results when they began to deviate significantly from our goals. From that point on, we realized that reference tracking was helping us find the most meaningful and applicable articles.

During our search, we also realized that we needed to expand our thinking to include articles which provided supportive evidence for the need for or efficacy of follow-up programs and therefore we included this in our clinical scenario above. We wanted to include these articles to give context and meaning to the articles we found and support the crucial nature of Valley Medical Center's NICU follow-up program.

Articles shown in the rejected columns below were rejected for not fully meeting inclusion criteria, including deviation from the client population of discharged NICU infants in a follow-up program.

We began by meeting with Eli to explore resources such as RefWorks, ILL, UW Tacoma and UW Seattle. He also taught us how to make our search more efficient and how to navigate databases to obtain the full texts of interesting articles. We met with Dr. Pitonyak, our project chair, who gave us valuable and relevant information based upon her

experience with NICU infants. She gave us ideas on where to take our research (i.e. new search terms) and provided us with other textbook resources and an AOTA fact sheet to further our knowledge of the subject.

In January 2017 we performed additional searches, reducing our search criteria to include articles from 2015-2017 to ensure no new research had been published since our initial draft. Searching across multiple databases, no additional articles were found.

## Results of Search

**Table 1. Search Strategy of databases.**

Search Terms	Date	Database	Initial Hits	Articles Excluded	Total Selected for Review
NICU FOLLOW UP PROGRAM	9/22/16	Primo	36	34	2
NICU FOLLOW UP PROGRAM	10/6/16	PubMed	121	121	0
NICU DEVELOPMENTAL FOLLOW UP PROGRAM	10/13/16	Primo	25	24	1
NICU OUTPATIENT DEVELOPMENTAL FOLLOW UP PROGRAMS	10/13/16	Google Scholar	16,900	N/A	2
{NICU FOLLOW-UP} AND {OCCUPATIONAL THERAPY}	10/15/16	PsycINFO	1	1	0
NICU FOLLOW-UP PROGRAM	10/15/16	PsycINFO	1	1	0
{NEONATAL INTENSIVE CARE UNIT} AND {FOLLOW-UP}	10/15/16	PsycINFO	213	205	5 3*
{NEONATAL INTENSIVE CARE UNIT} OR {NICU}	10/15/16	OTsearch	60	60	0

{NEONATAL INTENSIVE CARE UNIT} OR {NICU} AND {OCCUPATIONAL THERAPY} AND {FOLLOW-UP}	10/15/16	Nursing and Allied Health Database	569	566	3*
{NEONATAL INTENSIVE CARE UNIT} AND {DISCHARGE} AND {FOLLOW-UP}	10/15/16	Medline	199	198	1
{NEONATAL INTENSIVE CARE UNIT} AND {FOLLOW-UP PROGRAM}	1/23/17	Primo	14	14	0
{NICU} AND {POST-DISCHARGE FOLLOW-UP}	1/23/17	PubMed	11	11	0
{NEONATAL INTENSIVE CARE UNIT} AND {FOLLOW-UP} AND {PROGRAM}	1/23/17	Nursing and Allied Health Database	54	54	0 1*
{NEONATAL INTENSIVE CARE UNIT} AND {FOLLOW-UP} AND {ADHERENCE}	1/23/17	Medline	8	8	0
{NEONATAL INTENSIVE CARE UNIT} AND {FOLLOW-UP} AND {PROGRAM}	1/23/17	PsychInfo	7	7	0 2*
{NEONATAL INTENSIVE CARE UNIT} AND {FOLLOW-UP}	1/23/17	Medline	150	150	0 3*
Total number of articles used in review from database searches = 11					

\*article excluded because it came up in a different search and was already included in the CAT

For exclusion reasons, see below.

**Table 2. Articles from citation tracking.**

Article	Date	Database	Initial Hits	Articles Excluded	Total Selected for Review
Kuppala, Tabangin, Haberman, Steichen, & Yolton (2011)	9/22/16	ProQuest	7	5	2
Total number of articles used in review from citation tracking = 2					

\*article not used in CAT table due to one or more reasons: failed to meet inclusion criteria, met exclusion criteria, was a review of an original study, or irrelevant to topic.

**Table 3. Articles from reference tracking.**

Article	Date	Articles Referenced	Articles Excluded	Total Selected for Review
Bockli, Pellertie, & Meadow (2014)	10/18/16	13	12	1
Dorling & Field (2006)	10/18/16	36	35	1
Ballantyne, Stevens, Guttman, Willan, & Rosenbaum (2014)	10/22/16	27	26	1 5*
Ballantyne, Stevens, Guttman, Willan, & Rosenbaum (2012)	11/12/16	34	34	6*
Ballantyne, Benzies, Rosenbaum, & Lodha (2014)	11/12/16	35	34	1 6*
Total number of articles used in review from reference tracking = 4				

\*article not used in CAT table due to one or more reasons: failed to meet inclusion criteria, met exclusion criteria, duplicate of article that was already used, or irrelevant to topic.

Total number of articles used in review from database searches = 11

Total number of articles used in review from citation tracking = 2

Total number of articles used in review from reference tracking = 4

Total number of articles used in review from UPS Master's Thesis = 0

Total number of articles used in CAT = 17

*Summary of Study Designs of Articles Selected for the CAT Table*

<b>Pyramid Side</b>	<b>Study Design/Methodology of Selected Articles</b>	<b>Number of Articles Selected</b>
Experimental	_0_Meta-Analyses of Experimental Trials _3_Individual Randomized Controlled Trials _0_Controlled Clinical Trials _0_Single Subject Studies	3
Outcome	_0_Meta-Analyses of Related Outcome Studies _2_Individual Quasi-Experimental Studies _3_Case-Control Studies _1_One Group Pre-Post Studies	6
Qualitative	_0_Meta-Syntheses of Related Qualitative Studies _0_Small Group Qualitative Studies _0_brief vs prolonged engagement with participants _0_triangulation of data (multiple sources) _1_interpretation (peer & member-checking) _0_a posteriori (exploratory) vs a priori (confirmatory) interpretive scheme _0_Qualitative Study on a Single Person	1
Descriptive	_0_Systematic Reviews of Related Descriptive Studies	5

	<p>_5_ Association, Correlational Studies</p> <p>_0_ Multiple Case Studies (Series), Normative Studies</p> <p>_0_ Individual Case Studies</p>	
Unrated	2 Evaluation papers	2
<p>Comments: We had a fairly good distribution of the four different types of research, although we have a distinct lack of qualitative research, which we found surprising.</p> <p>It is logical that there are fewer AOTA level III studies because it is difficult to do one-group pre and post-test studies when it comes to ethically providing NICU follow-up services.</p> <p>Many of the studies identified a lack of experimental research done to support NICU follow-up program efficacy which could be a reason why there are few meta-analyses on this topic.</p> <p>Three of the articles were unrated evaluations and are therefore not represented in the tallies above or the AOTA levels below.</p> <p>AOTA Levels:</p> <p>I- 3                  II- 4                  III- 1                  IV- 7                  V- 2</p>		<i>TOTAL = 17</i>

**Table 4. Summarizing the Qualitative Evidence**

Author, Year, Journal	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Methods for enhancing rigor	Themes and Results	Study Limitations
<b>Facilitators/Barriers to Service Utilization</b>						
Ballantyne, Benzies, Rosenbaum, & Lodha (2014)  Child: Care, Health, and Development	Identify barriers and facilitators to att at NFU pgms in Canada, viewpoint of mothers and HCPs.	Qualitative phenomenological descriptive, Level IV, Q2	n = 12, mothers from two NFU pgms.  n = 20, HCPs recruited through the Canadian Neonatal Follow-Up Network from 9 NFU pgms. Represented a variety of experience and professions.	Code-recode, member checking, triangulation, prolonged engagement, interviewer training.	<b>Barriers:</b> feelings of vulnerability, fear of bad news and cumulative interplay between mother’s feelings of isolation and being overwhelmed, having limited support/resources, and perception of not needing NFU until problems arose.  <b>Facilitators:</b> perceiving a greater sense of control over preventing and managing child’s problems, support, family-centered care, and having adequate resources.	The small sample size is generalizable only to other English speaking, non-immigrant mothers who have similar characteristics to the mothers included in the study.

NFU = NICU follow-up, pgm = program, att = attendance, HCP = health care professional

Table 5. Summarizing the Quantitative Evidence

Author, Year, Journal	Study Objectives	Study Design/ Level of Evidence	Participants: Sample Size, Description Inclusion and Exclusion Criteria	Interventions & Outcome Measures	Summary of Results	Study Limitations
<b>Facilitators/Barriers to Service Utilization</b>						
Campbell, Halinda, Carlyle, Fox, Turner, & Chance (1993)  American Journal of Epidemiology	Examine factors associated w/ NFU att.	Retrospective cohort study, Level II, O3	n =369 VLBW infants (<1,500 g) <b>IC:</b> resident of Southwest Ontario, VLBW <b>EC:</b> infants w/ congenital conditions influencing development	Retrospective medical chart review of both maternal and newborn demographics. Multivariate analysis of risk factors for att. Predictive and proportional odds model also used to assess att risk factors.	<b>Factors associated w/ increased att:</b> Close proximity to NFU services, neonatal anemia, birth wts <1,000 g. Infants perceived to be at highest risk of developmental delays due to LBW/ other adverse neonatal events until 18 mos corrected age. <b>Factors associated w/ decreased att:</b> single mothers less than 20 years old, not born in a tertiary center.	Potential to incorrectly classify outcomes and risk factors. Age at which infants first visited the NFU was variable. Findings about att considered to be viewed as “hypothesis testing”.
Nehra, Pici, Visintainer, & Kase (2009)  Journal of Perinatal Medicine	Identify factors which affected NFU att.	Retrospective cohort study, Level IV, O2	n = 298 pts d/c and referred to regional neonatal follow-up pgm 7/1/06 - 6/30/07.	Subjects were categorized as compliant or noncompliant. 16 pt descriptives and 12 pt morbidities were compared. Descriptive categories included: birth information, maternal factors, pt care needs, and pt transfer.	<b>Factors associated w/ increased att:</b> older maternal age (>30), EI referral, and decreased latency of patient contact after d/c. None of the pt morbidities or gestational age at birth significantly affected att rates. <b>Factors associated w/decreased att:</b> maternal drug use during pregnancy and pt transfer outside of NICU.	Only able to assess antenatal, neonatal, preterm status and patient transfer status. Socioeconomic data was not available for assessment.

<p>Ballantyne, Stevens, Guttman, Willan, &amp; Rosenbaum (2014)</p> <p>Child: Care, Health, and Development</p>	<p>Identify maternal and infant factors predictive of NFU att.</p>	<p>Descriptive cohort, Level IV, D3</p>	<p>n = 357 mothers and n = 400 infants  <b>IC:</b> Preterm birth (&lt;1500 g or term/near term birth or &lt;3rd percentile for GA), multiple births, complex medical needs/surgeries.  <b>EC:</b> Mothers who could not speak or read English, were extremely ill or hospitalized, did not have custody.</p>	<p>NFU appts scheduled before d/c at one of two sites; parents given reminder cards. Mailed reminders sent before first appt. Telephone reminders for all subsequent appts.  <b>O:</b> Demographic and clinical characteristics collected from medical record; mother demographic characteristics and social context collected via questionnaire booklet. Att tracked at first 3 scheduled appts.</p>	<p><b>Predictive factors for att:</b> mothers who had higher mean stress scores, higher ratings of perceived risk of developmental issues w/ infant, and higher intention to attend NFU.  <b>Predictive factors for nonatt:</b> single mothers, younger mothers, mothers worried about maternal alcohol or drug abuse, and distance from NFU.  <b>Other:</b>  No significant difference found for infant factors. SES not a predictive factor of att despite single mothers having significant differences in SES measures compared to two parent families.</p>	<p>“Social desirability bias” may result in under-reporting on drug/alcohol questionnaires.</p> <p>Findings can only be generalized to populations w/ similar characteristics and who have access to universal healthcare coverage such as that in Canada.</p>
<p>Tien, Peterson, &amp; Shelley (2002)</p> <p>Journal of Early Intervention</p>	<p>Identify patterns of service use and the influence of demographic variables, parents’ perceptions of problems, and enabling variables on service use by families of infants d/c from NICU.</p>	<p>Survey, Level IV, D3</p>	<p>n = 84 mothers and n = 1 father of infants attending a high risk NFU.  <b>IC:</b> Infant born &lt; 37 weeks GA, NICU graduate, &lt; 24 months, eligible for NFU.  <b>DI:</b> 94% white, 83% married, 74% &gt; high school education, 49% urban.  Average income: \$30,000-39,000.  Average age: 27.4 yrs.</p>	<p>Information regarding demographic variables, parental perceptions of child problems and support needs, enabling variables, and other factors collected by Service Utilization Questionnaire. Families’ perceived needs for support and assistance measured by Support Functions Scale.</p>	<p><b>Factors associated w/ increased att:</b> contact w/ a NICU social worker and perceived their child to have health concerns.  <b>Factors associated w/decreased att:</b> parents reported children did not have any health concerns in the last 3 months.  Most common reason for not utilizing NFU service was “I don’t want it.” No demographic variables associated w/ service use.</p>	<p>Small size/ homogeneity of sample limits generalizability and many variables may have increased possibility of Type I errors.  “Readability level/ visual format” of survey may have led to incomplete responses.</p>
<p>Harmon, Conaway,</p>	<p>Identify factors influencing</p>	<p>Survey/ retrospective</p>	<p>n = 133 infants  <b>IC:</b> d/c from NICU</p>	<p>Maternal variables, family variables, and patient</p>	<p><b>Factors associated w/ att:</b> greater number of days on oxygen, longer</p>	<p>Findings can only be generalized to similar</p>

Sinkin, & Blackman (2013)  Clinical Pediatrics	NFU att.	cohort, level IV, D3	11/1/09- 8/1/10, scheduled for NFU appts <b>EC:</b> infants scheduled for specialized follow-up or not referred to NFU.	factors identified via electronic medical record and compared b/w compliant and noncompliant families. Reasons for noncompliance identified by telephone survey of noncompliant families.	stay, presence of chronic lung disease. <b>Factors associated w/ nonatt:</b> maternal drug use, multiple gestation pregnancy, male sex of infant, greater distance from hospital.	populations.  Narrowly defined “noncompliant” as never having attended a NFU appt and so did not distinguish differences between families that had delayed compliance.
<b>Comprehensive Care Program Outcomes</b>						
Broyles, Tyson, Heyne, Heyne, Hickman, Swint, ... Ahn (2000)  Journal of the American Medical Association	Assess if comprehensive follow-up care is as cost-effective and yields positive outcomes compared to routine care of high-risk inner-city infants.	RCT, Level I, E2	<b>Tx:</b> n = 448 infants. <b>Control :</b> n = 441 infants <b>IC:</b> born at Parkland Memorial Hospital, <1000 g birth weight, 1001-1500 g and mechanical ventilation w/in 48 hrs of birth. <b>EC:</b> Died before nursery d/c, d/c after 1 yr, moved out of country, adopted out of country. <b>DI:</b> More than 80% of mothers were black or Hispanic. Method of randomization unspecified.	<b>Tx:</b> Comprehensive follow-up care: available 5 days/wk, medical staff available 24/7, taxi rides to ED as needed, follow-up call after ED visits. Staff met w/ mother at enrollment and d/c. Foster grandmother of matching SES and race provided to augment parent education. <b>Control:</b> routine follow-up care <b>O:</b> Hospital admittance/contact, death rates, cost of comprehensive care program, and att.	Tx group: average of 3.1 more hospital clinic visits and 6.7 more telephone contacts w/ staff, 20% fewer dropouts from NFU pgm, fewer ED visits, 47% fewer developed life-threatening illnesses, and 19 fewer infants had unknown outcomes and deaths.  Increased cost of comprehensive NFU care significantly reduced costly intensive care visits, making the program more cost-effective than routine care.	Extrapolated data. Same staff provided tx. May not generalize to more poorly-staffed facilities. Some costs were not calculated such as cost to the family for work time lost or clinic visits outside of the hospital.
Constantine, Haynes, Spiker,	Examine recruitment and retention	RCCT, Level I, E2	n = 985 LBW (<2500 g) and premature (GA < 37 weeks) infants.	<b>Control:</b> 3 yr pediatric follow-up <b>Tx:</b> 3 yr pediatric NFU	<b>Factors associated w/ retention:</b> Lighter-wt infants /younger maternal age interacted. Heaviest	Findings may only apply to LBW infants, limited generalizability.

<p>Kendall-Tackett, &amp; Constantine (1993)</p> <p>Journal of Developmental and Behavioral Pediatrics</p>	<p>of LBW infants in a 3 yr RCCT to determine efficacy of EI program in reducing health and behavioral problems.</p>		<p>Stratified by 8 sites, grouped by wt. (&lt;2000 g and 2001-2500 g). 1/3 of each group randomly assigned to tx group and 2/3 assigned to follow-up group. Medical sites located in urban, high-risk, low SES areas. <b>EC:</b> infants w/ severe medical impairments that may not benefit from EI, non-English speaking mothers, mothers who reported drug/alcohol abuse or psychiatric hospitalizations.</p>	<p>pgm w/ comprehensive EI. 1.5-3 hr appts. Used tracking procedures, incentives, and remuneration for services. If unable to return to clinic, partial assessments led via phone or satellite clinics. <b>O:</b> Recruitment bias/non-enrollment, assessed via multiple logistic regression Retention bias assessed w/ Cox Proportional Hazards model.</p>	<p>infants more likely to be retained in control group than tx. Oldest mothers more likely to be retained in follow-up than tx group. <b>Reasons for dropout:</b> Unknown whereabouts, refused participation, infant deceased, moved away/lost contact. Mothers w/ less education more likely to drop out. <b>Tx had no significant effect on retention.</b></p>	<p>EC further limits generalizability. Due to retrospective nature of study from 23 years ago, history effects may affect contemporary validity.</p>
<p>Bryson, Theriot, Ryan, Pope, Tolman, &amp; Rhoades (1997)</p> <p>Journal of the American Dietetic Association</p>	<p>Determine effect of multi-disciplinary NFU services for VLWB infants.</p>	<p>Case-controlled study. Level II, O3</p>	<p><b>Tx:</b> CC clinic, 09/15/92-06/06/93 n = 33 infants <b>Control:</b> General pediatric clinic, 09/15/91-09/14/92 n = 42 infants <b>IC:</b> born in NICU or admitted w/in 48 hours of birth; &lt;1500 g birthweight. <b>EC:</b> Multiple congenital anomalies, genetic syndromes, or died in NICU.</p>	<p><b>Tx:</b> CC clinic; appts every 2 mos w/ calls to ensure att, gave 2<sup>nd</sup> chances for missed appts. Received multidisciplinary care. Scheduled more frequent appts prn. <b>Control:</b> General pediatric clinic received infrequent follow-up with HCP who decided need for OT/SLP, nutritionist tx. <b>O:</b> Att.</p>	<p>Loss of only 10% of participants w/in 1 yr. Supports efficacy of multidisciplinary team providing primary care during a NFU pgm as compared to general care for at-risk VLBW NICU infants using developmental outcomes. Supports efficacy of multidisciplinary team including dietitian, calling to confirm appts and providing any extra appts needed for positive outcomes.</p>	<p>Small sample size. Missing data for control infants. Voluntary recruitment skewed data. Authors did not randomize despite opportunity. Groups recruited during different time periods. Cannot determine causality of multidisciplinary team effect on developmental outcomes.</p>
<p>Waruingi, Iyer, &amp; Collin</p>	<p>Examine effectiveness</p>	<p>Retrospective case-control,</p>	<p><b>Tx:</b> n = 85 VLBW infants</p>	<p><b>Tx:</b> Comprehensive d/c plan w/ well-coordinated,</p>	<p>Infants in tx group made fewer unscheduled visits to urgent care</p>	<p>Results based on retrospective data</p>

(2015) World Journal of Pediatrics	of Special Care Developmental Follow-up Clinic in improving healthcare usage of VLBW infants discharged from a NICU.	II, O3	<b>Control:</b> n = 85 infants <b>Tx IC:</b> VLBW infants w/ < 32wks gestation born between 1/1/08-12/31/08 <b>Control IC:</b> healthy infants born at >36wks gestational age 1/1/08-12/31/08, not requiring NICU. <b>Control EC:</b> Did not receive primary care at the institution during first yr.	multidisciplinary services and communication w/ a clinic coordinator who scheduled future visits and ensured att via phone calls and letters. <b>Control:</b> d/c after standard care, assigned PCP. <b>O:</b> number of scheduled and unscheduled health-care visits compared between groups	and fewer unscheduled visits in general. Number of ER visits not significantly different.	collected over a short period of time. Using healthy infants may not have been an appropriate control to compare VLBW infants in the NFU program.
<b>Investigating Methods for Increasing Attendance</b>						
Patra, Greene, Perez, & Silvestri (2014)  e-Journal of Neonatology Research	Compare NFU pgm att rates of VLBW infants before and after clinic changes designed to increase att, as well as examine reasons for non-att.	Retrospective chart review. Level III, O4	n = 720 VLBW infants born 1/1/04-12/31/09 in NICU. Excluded if participating in a different NFU.	<b>I: 2007-2008:</b> frequent reminder calls, change session to 1-day vs 2, discontinue morning appts, schedule regardless of prior att. <b>2008-2009:</b> discontinue time-consuming paperwork, schedule appts while still in NICU, give 3 opportunities to make appt, restrict to VLBW only. <b>O:</b> Descriptive statistics including number of appts made and reasons for non-compliance.	Intervention correlated w/ a change of reasons for non-att from lack of interest or refusal to specific distance or insurance issues. Overall compliance in att increased significantly. Mothers still nursing attended more appts. Early follow-up appts were attended more frequently than later appts. Early morning, late-afternoon and Friday appts were poorly attended.	Difficulties w/ generalizability, despite large sample size. Tx implemented may not be feasible at other facilities. Findings may not generalize to local, smaller hospitals. Study sample was solely VLBW infants, not other children who may be in the NICU.
Robinson, Gund,	Determine effectiveness	RTC, Level I, E2	n = 89 families <b>IC:</b> families w/ infants	<b>Tx:</b> Communication between families and	Frequency of scheduled hospital appts per day of home health care	Only 83% of the control group and 68% of the

<p>Sjoqvist, &amp; Bry (2016)</p> <p>Acta Paediatrica</p>	<p>of telemedicine in the follow-up of infants discharged from a NICU to home health care to decrease the need for scheduled or ER visits.</p>		<p>d/c from NICU to home care b/w 2012-2013.  <b>EC:</b> unable to speak Swedish, no access to computer/ internet at home, and infants needing control visits for less than a week.</p>	<p>HCPs via web application/video calls. Web application included daily questions regarding infant's health/nutrition/parent coping  <b>Control:</b> standard health care after d/c  <b>O:</b> Family perspective of home health care measured via survey</p>	<p>and number/ frequency of emergency visits significantly lower in telemedicine group. 85% of families felt video calls easy to use, 92% felt it was easy to communicate. 78% felt video calls decreased need for hospital visits, 48% felt video calls important. 84% felt web application was good, 100% felt easy to use. About half felt web application reduced need for hospital visits.</p>	<p>telemedicine group responded to the questionnaire, which could have caused a bias in the data on the parent's opinions. Findings can only be generalized to healthcare systems similar to Sweden's.</p>
<p>Catlett, Thompson, Johndrow, &amp; Boshkoff (1993)</p> <p>Public Health Reports</p>	<p>Analyze how demographic, biomedical, and psychosocial factors affect "appt keeping" at NFU pgms.</p>	<p>Level II, O2, population based quasi-experimental</p>	<p>n = 130 mothers/ infants recruited from ongoing study on VLBW infants  <b>IC:</b> infant wt. &lt; 1,500 g, family lives in 10-county area  <b>EC:</b> infants w/ congenital diseases/ syndromes</p>	<p>Demographic, biomedical, and psychosocial data obtained in NICU.  <b>Tx:</b> Interventions to encourage parent participation: bond mothers to staff, parents have access to infants' assessments, and transportation provided as needed.  <b>O:</b> Att rate</p>	<p>Transportation found to be effective tx, reduces long term health care costs. Not attend 24-month checkup: less likely to be married, more likely to be non-white, higher GA, lower maternal intelligence, lower efficacy ratings. No significant difference in SES, birth wt, stress ratings, or coping methods. Participants who did not attend 6-mo checkup had higher maternal ratings of daily stress. Highest risk for dropping out associated w/ maternal daily life stressors.</p>	<p>Only recruiting VLBW infants limits generalizability. VLBW infants already involved in another study, which may have had additional criteria that further limits the generalizability. 69.2% of mothers and infants are non-white, not specified. Accurate demographics unknown. Age of study may affect contemporary validity</p>

## NICU Follow-Up

Attendance Patterns						
Ballantyne, Stevens, Guttman, Wilan, & Rosenbaum (2012)  Journal of Perinatal and Neonatal Nursing	Assess patterns of NFU att, identify at what points mothers and infants withdrew from NFU pgms.	Descriptive cohort, Level IV, D3	n = 357 mothers, 400 infants <b>IC:</b> Mothers w/ infants w/ preterm birth (BW<1500 g or term/near term birth or <3rd percentile for GA), multiple births, complex medical needs/surgeries. <b>EC:</b> Mothers who could not speak/ read English, were extremely ill/ hospitalized, and/or did not have custody of their infant.	NFU appts scheduled before d/c at one of two sites; parents given reminder cards. Mailed reminders sent before first appt. Telephone reminders for all subsequent appts. <b>O:</b> Demographic and clinical characteristics collected from medical record; mother demographic characteristics/social context collected via questionnaire booklet. Att tracked at first 3 scheduled appts.	9% of mothers/infants never attended NFU, 10% attended 1 appt, 16% attended 2/3 appts, 65% attended all appts. -If only attended 1 appt, often withdrew early. -Att decreased over time; 84% attended 1st appt, 74% attended 3rd appt. -Greatest withdrawal occurred after d/c, followed by after 1st appt.	Findings can only be generalized to populations w/ similar characteristics and who have access to universal healthcare coverage such as that in Canada.
Survey of NFU Directors						
Bockli, Andrews, Pellerite, Meadow (2014)  Journal of Perinatology	Identify patterns of care and struggles in NFU clinics both in private and academic settings.	Survey, Level IV, D3	n = 183, anonymous internet survey sent to NFU clinic directors (n = 89 academic, n = 94 private). <b>IC:</b> NFU clinic directors listed in the directory of NICUs published by American Academy of Pediatric Section on Perinatal Pediatrics. No identified exclusion criteria.	Survey consisted of 30 questions. Categories: NFU Clinic, appts scheduled, clinic characteristics, pt demographics, medical care in NFU Clinic, NFU clinic and research, quality assurance, and improving outcomes.	Both academic and private settings have similar goals for NFU programs to reduce readmissions, reduce inpatient LOS, improve coordination of care, and relieve future burden on the healthcare system. Most NFU directors feel that coordination of care could be improved by increased funding and that this would result in lower health-care costs in the long term while improving outcomes.	High rate of non-response.  Survey may not have been all inclusive of relevant data.  Surveys may not have been sent to the most appropriate person due to method of identifying respondents.

VLBW = very-low birth weight, EI = Early intervention, DI = descriptive information, LOS = Length of stay, CAN = Canada, IFSP = Individualized Family Service Plan, IC = inclusion criteria, EC = exclusion criteria, LBW = low birth weight, RCCT = randomized controlled clinical trial, wt = weight, CP = cerebral palsy, att = attendance, pgm = program, GA = gestational age, pt = patient, NFU = NICU Follow-Up, d/c = discharged, O = outcomes, HCP = health care provider, PCP = primary care provider, CC = comprehensive care

**Table 6. Summarizing the Unrated Evidence**

Author, Year, Publication	Topic	Professional Qualifications of Expert	Type of Article	Theme, Main Idea	External Lit.	Key Points	Limitations, Shortcomings, Critique
<b>Expert Opinion</b>							
Gong, Johnson, Livingston, Matula, & Duncan (2015)  Maternal Health, Neonatology, and Perinatology	Discuss developmental follow-up practices in Texas, provide recommendations for achieving quality comprehensive follow-up care.	4 academic, 3 non-academic NFU directors, as well as: representatives from the NICHD, the Texas Department of Assistive and Rehabilitative Services' Early Childhood Intervention (EIC) program, and Hand to Hold (a family advocacy group).	Expert opinion	Participants attended 1-day summit to discuss NFU practices in Texas. Topics included general review of practices, key challenges faced, recommendations for addressing challenges, qualities of CC.	Y	<b>Challenges identified:</b> systemic problems impacting access and use <b>Quality program components:</b> multidisciplinary team, support for case management and home visits, standardized manual of operations, processes to share data w/ primary care providers, mechanisms for tracking, family support groups, website w/ resources for families/providers/community, and an appropriate clinic space. <b>Recommendations (only relevant included):</b> arrange follow-up visits before d/c, give educational materials in multiple modalities, help parents learn how to engage w/ HCPs, continue follow-up support w/ outpatient care, home visits, phone calls.	Only involved HCPs from Texas programs.
Hussey-Gardner, McNinch, Anatsi, & Miller (2012),  Neonatal Network	Maryland's PRIDE program including multidisciplinary, inpatient, outpatient, and EI services.	<b>Hussey-Gardner:</b> Dev. specialist. PRIDE director, UMMS NFU, PhD <b>McNinch:</b> BITP consultant, doctoral student special ed, MS health sciences <b>Anatsi:</b> NCC RN, MSN perinatal/neonatal clinical nurse specialist. <b>Miller:</b> PRIDE service coordinator	Program review paper	PRIDE connects UMMS to BITP. PRIDE referral for EI services can be made from NICU or NFU. PRIDE staff consists of a developmental specialist and service coordinator.	Y	Key components of PRIDE: liaison, <b>on-site coordinator</b> , and staff education. Onsite coordinator is essential to <b>maintain consistency</b> from NICU to NFU to BITP. Letter provided in NICU from "infant" on benefits of PRIDE and BITP, <b>ensures initial contact w/ family</b> . NFU staff: Multidisciplinary rehab team UMMS NFU has more flexible criteria than BITP, allowing it to monitor infants before they qualify. Other themes: <b>Contact w/ family</b> - bedside posting, service coordinator contact; <b>Cultural competence</b>	Large, well connected hospital, limits generalizability.

PRIDE = Premature Developmental Infant Enrichment, UMMS = University of Maryland Medical Systems, BITP = Baltimore Infants and Toddler Program, UM = University of Maryland, BSN = Bachelor of Science in Nursing, NCC = National Certification Corporation, RN = registered nurse, MPH = master of public health, MA = Master of Arts, BS = Bachelor of Science, PCP = primary care physician, rehab = rehabilitation, dept = department, ed = education, dev = developmental

## Summary of Key Findings:

### Facilitators/Barriers to Service Utilization

Factors associated with underutilization of NICU follow-up services include: maternal feelings of vulnerability and feeling overwhelmed, having limited support/resources, and perception of not needing services until problems arise (Ballantyne, Benzies et al., 2014); infants not born in tertiary center (Campbell et al., 1993); being a single mother and/or a younger mother (Ballantyne, Stevens et al., 2014; Campbell et al., 1993; Catlett et al., 1993); lower maternal intelligence, lower parental self-efficacy, and higher maternal stress ratings (Catlett et al., 1993); maternal drug use (Ballantyne, Stevens et al., 2014; Campbell et al., 1993; Harmon et al., 2013; Nehra et al., 2009); multiple gestation pregnancy, male sex of infant (Harmon et al., 2013); greater gestational age and greater distance from clinic/hospital (Ballantyne, Stevens et al., 2014; Harmon et al., 2013).

Factors associated with utilization of NICU follow-up services include: having support, adequate resources, and family-centered care (Ballantyne, Benzies et al., 2014); older maternal age (Campbell et al., 1993; Nehra et al., 2009); EI referral and latency of patient contact after discharge (Nehra et al., 2009); high maternal stress and high intention to attend NICU follow-up (Ballantyne, Stevens, et al., 2014); contact with NICU social worker (Tien et al., 2002); greater number of days on oxygen and longer NICU stay (Harmon et al., 2013); close proximity to NICU follow-up services (Campbell et al., 1993; Harmon et al., 2013); parents perceiving their infant to have health problems. (Ballantyne, Benzies et al., 2014; Ballantyne, Stevens et al., 2014; Campbell et al., 1993; Harmon et al., 2013; Tien et al., 2002).

### Comprehensive Care Program Outcomes

Comprehensive, multidisciplinary care is an effective deterrent of NICU follow-up dropout, reducing costly ER visits and making comprehensive care more cost-effective than routine care (Broyles et al., 2002; Bryson et al., 1997). Specifically, comprehensive care can increase follow-up visits to and contact with the hospital while increasing retention and reducing ER visits (Broyles et al., 2002; Bryson et al., 1997). In addition, implementing a low-cost, practical model of comprehensive follow-up care can lead to fewer unscheduled visits to the hospital or urgent care clinic (Waruingi et al., 2015).

Another study identified risk factors for dropout from a comprehensive care NICU follow-up study, including young maternal age and a lower education status (Constantine et al., 1993). A significant interaction was found between infant birth weight and maternal age that predicted retention in the intervention group. Black and Hispanic mothers were more likely to enroll in the study than white mothers. The intervention of including comprehensive EI with the standard three-year pediatric care was not found to have an effect on retention (Constantine et al., 1993).

### **Investigating Methods for Increasing Attendance**

Three studies identified interventions that could increase attendance of NICU follow-up programs including systematic changes, utilizing telemedicine, and providing transportation to appointments (Catlett et al., 1993; Patra et al., 2014; Robinson, Gund, Sjoqvist, & Bry, 2016). Systematic changes included: calling before appointments, eliminating morning appointments, getting rid of time-intensive paperwork and scheduling appointments while mothers were still in the NICU (Patra et al., 2014). Contact with healthcare professionals via telemedicine reduced frequency of emergency visits and overall healthcare costs, in addition to participants reporting that they felt communication mediums were accessible and easy to use (Robinson et al., 2016). Providing transportation to NICU follow-up appointments increased attendance and reduced long term health care costs (Catlett et al., 1993).

### **Attendance Patterns**

One study investigated attendance patterns in a NICU follow-up program and found that 9% of mothers/infants never attended appointments, 10% attended one appointment, 16% attended 2 or 3 appointments, 65% attended all appointments (Ballantyne et al., 2012). Attendance decreased over time; 84% attended the first appointment and 74% attended the third appointment. Families were more likely to withdraw from services after discharge, before the first appointment (Ballantyne et al., 2012).

### **Expert Opinion**

One article identified components of a quality NICU follow-up program including: multidisciplinary team, support for case management and home visits, standardized manual of operations, processes to share data with primary care providers, mechanisms for tracking, family support groups, organized educational program for outreach to families/providers/community, website with resources for families/providers/community, and an appropriate clinic space (Gong, Johnson, Livingston, Matula, & Duncan, 2015). They also provided recommendations to improve programs such as: arranging follow-up visits before discharge, giving educational materials in multiple modalities, helping parents learn how to engage with healthcare professionals, and continuing follow-up support with outpatient care, home visits, and phone calls (Gong et al., 2015).

Another article discussed the teaming between hospital and early intervention institutions to maintain continuity of care (Hussey-Gardner, McNinch, Anatasi, & Miller, 2012). The most important concepts identified were: having a service coordinator who maintains contact with the family from the NICU through the infant's third birthday, ensuring initial family contact with bedside letter posting, and providing culturally competent care (Hussey-Gardner et al., 2012).

The final expert opinion article found that both academic and private settings have similar goals for NICU follow-up programs: reducing readmission and inpatient length of stay,

improving coordination of care, and relieving future burden on the healthcare system with reduced long-term health care costs (Bockli, Andrews, Pellerite, & Meadow, 2014).

### **Implications for Consumers:**

The consumers for the NICU follow-up service are infants who have been discharged from the NICU and their parents or guardians. This is the patient population that we researched. The research shows overwhelmingly that attending a NICU follow-up program provides a valuable bridge between the NICU and Early Intervention services to improve outcomes for the infants and their families. Consumers should demand education and the services that their children need to understand all of the benefits of attending and utilizing the NICU follow-up program. Although demographic barriers and contextual factors such as high stress levels or lack of social support can make attendance difficult, consumers should be aware that attending a NICU follow-up program leads to improved developmental outcomes and less need for additional services.

### **Implications for Practitioners:**

The results of this research have implications for all practitioners involved in NICU follow-up programs, including nurses, doctors, occupational therapists, physical therapists, speech language pathologists, and others. These multidisciplinary teams share the common goal of ensuring infants being discharged from the NICU are returning for follow-up appointments in order to assess their health and development. Identifying the factors influencing why families would not be utilizing follow-up services is the first step in implementing program changes that would increase service utilization. Based on the factors identified, the literature provided a variety of suggestions for increasing NICU follow-up service utilization.

Suggestions related to appointment scheduling included: scheduling all follow-up appointments before discharge, giving multiple chances to make appointments, scheduling appointments later in the day, having a social worker or coordinator meet with and discuss discharge plan with families, providing appointment reminder cards, providing a “baby” letter, and/or calling or sending reminder letters. Suggestions related to client education and support included: ensuring families understand the importance and need for attending follow-up services, providing education in multiple modalities, and providing a “foster grandmother” to families. Suggestions related to environmental factors included: providing transportation to/from clinic, having a mobile clinic, and utilizing telemedicine. This information could contribute to the development of a standard NICU follow-up protocol practitioners could implement to mitigate the common factors leading to decreased attendance to follow-up services and thus maximize utilization of these services by families.

### **Implications for Researchers:**

Future research should include experimental and qualitative design, investigate complex factors affecting attendance such as drug or alcohol abuse, psychiatric conditions, and address relevant contemporary attendance factors. Evidence may be improved by ensuring high quality studies employing methods of high rigor, while investigating the lived experience of NICU/NFU parents. Additionally, quantitative evidence may be improved by expanding the population assessed to include mothers with drug/alcohol abuse, infants with neonatal abstinence syndrome (NAS), and those who don't speak English; these are incredibly relevant factors for healthcare professionals. Practitioners need researchers to elaborate on why parents cannot or do not want to attend NFU through analyzing various systems and their dynamic interactions that may affect attendance (i.e. social, cultural, environmental, demographic).

Specific questions to be addressed by researchers:

- How do early intervention services affect NFU attendance?
- Does every infant who was in the NICU need to be referred to NFU? (i.e. if they are only in the NICU for 3 hours)
- How can multi-institutional teaming be facilitated to maintain the continuum of care?
- What is the feasibility of service coordinators to maintain family contact and continuity?
- How do rural and urban medical centers compare with their respective NFU attendance factors?

### **Bottom Line for Occupational Therapy Practice/ Recommendations for Better Practice:**

There is a large amount of research to support best practice for occupational therapists involved in or managing NICU follow up programs. In either role, the occupational therapist can utilize their skills to advocate for their follow-up program and utilize this research to make the program stronger and more efficacious by increasing attendance rates of consumers. The research shows that building a strong rapport with consumers is vital to their attendance and this therapeutic use of self is a skill that is inherent to occupational therapists. The occupational therapist should also use this research to be aware of factors that put individual consumers at higher risk for non-attendance and provide equitable care. He or she can advocate for increased attendance by sharing the research supporting provided transportation or emphasizing the need to schedule appointments for the follow-up program prior to NICU discharge. The occupational therapist can use his or her knowledge of team building to ensure that a multidisciplinary approach is used and advocate for utilization of a coordinator to ensure a continuum of care. Additionally, the occupational therapist should understand that the client includes the whole family, not just the infant, and that parental support groups could be very beneficial for the families and increase follow-up attendance.

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### **Involvement Plan**

We met with Dr. Kari Tanta on February 9th, 2017. She was excited to hear about the next phase of our project and listened carefully as we presented the knowledge translation options that we had brainstormed. We had prepared a list of several translation project ideas including: an app to track missed appointments, a texting service for clients, a client-run Facebook page, development of a NICU letter from baby, increased role of the social workers, or a support group for parents. Unfortunately, Dr. Tanta determined that these ideas would not be feasible or sustainable for VMC.

Dr. Tanta expressed that she was excited to share our CAT with her staff and felt that an in-service would not be necessary in order to do that. She suggested that, to create a meaningful product, we could alter our paper to fit the criteria for a column that she holds in Dr. Swinth's pediatric journal, *Journal of Occupational Therapy, Schools, and Early Intervention*. We will work in coordination with Dr. Tanta and Dr. Swinth to ensure that what we write will be of publishable quality, and she assured us the process would be streamlined given that it will be supported by the editors.

We also decided a second component to our translation project will be to meet with Dr. Tanta's group of University of Washington (UW) occupational therapy students. They are currently working on a practical project to create an educational video for parents of NFU infants, as well as creating a survey to help Dr. Tanta gather more information. We will use our meeting to share the knowledge we have gathered to help shape their survey with relevant demographic information, thus making their survey and education as efficacious as possible.

Lastly, Dr. Tanta introduced us to Leanna Birge, PhD, a new grant writer for VMC who is working to obtain funding for small QI studies, supporting the efficacy of the NFU programs

and contributing to research. We will collaborate with Dr. Birge by sharing our findings to guide her grant writing and to augment her knowledge as a newcomer to the team.

### **Context**

Our knowledge translation plan includes one informational product and two informational collaborations. The first product is an article in the *Journal of Occupational Therapy, Schools, and Early Intervention* detailing the results of our CAT table. The second product is to contribute to the development of a client survey that will gather data for the NICU team related to follow-up utilization. The informational collaboration will occur with Dr. Birge to share our findings with her to give her ideas for specific grant targets to implement with her QI studies.

The overall context for which we are attempting to implement a knowledge translation project is the VMC Children's Therapy Unit, which is a part of University of Washington Medical Center, a large hospital network. This network is run by a publicly elected board of commissioners, the UW Medical Board, and a CEO. In addition, there are rehabilitation managers overseeing each unit. In any attempt to implement suggestions during the knowledge translation process, it is important to consider the impact of the system's context (Nuyens & Lansang, 2006 as cited in Law & McDermid, 2014). Any major program changes will likely have to be approved across multiple levels of the network. Thus, the size and complexity of the organization mean that changes can be difficult to make and sustain. For this reason, Dr. Tanta was resistant to implementation of projects that would change the current NFU program and encouraged us to take a different direction in knowledge translation.

Given the nature of our project, the contextual factors influencing our process will be related to publishing an article in the *Journal of Occupational Therapy, Schools, and Early*

*Intervention* and collaborating with OT students from UW and Dr. Birge. Publishing the article will be dependent upon approval from Dr. Tanta and Dr. Swinth. Additionally, we must review previous column articles to ensure our article is written in the correct format and addresses a broader audience. Our level of involvement in the UW student's project is dependent upon the level of collaboration they desire, and how much of our research will be useful and applicable for them. Lastly, our collaboration with Dr. Birge is dependent on her prior knowledge of NFU programs and the relevance of our specific research question to the grants she is pursuing.

**Tasks/Products and Target Dates:**

<b>Task/Product (1a-f above)</b>	<b>Deadline Date</b>	<b>Steps w/ Dates to achieve the final outcome</b>
Column Article in <i>Journal of Occupational Therapy, Schools, and Early Intervention</i>	4/14/17	<ol style="list-style-type: none"> <li>1. Meet with Dr. Swinth to review journal articles with previously published CAT data. 2/23/17.</li> <li>2. Write first draft of article by and group peer edit. 2/27/17.</li> <li>3. Have draft submitted to Dr. Swinth, Dr. Pitonyak, and/or Dr. Watling by 3/6/17</li> <li>4. Make a final draft by 3/20/17</li> <li>5. Have final draft looked at by Dr. Tanta and/or Dr. Swinth 4/03/17</li> <li>6. Submit to Dr. Tanta by 4/14/17</li> </ol>
Meet with UW Students, provide brief paper to summarize the interaction and how the KT process went. Assist with formulating client survey questions.	4/26/17	<ol style="list-style-type: none"> <li>1. Email UW students to set up time to meet time 2/17/17.</li> <li>2. Per UW availability, plan to meet prior to 3/10/17. Draft reflections on intra-professional collaboration.</li> <li>3. Schedule meeting with Dr. Watling and Dr. Pitonyak to go over UW collaboration by 3/24/17.</li> <li>4. Submit draft to Dr. Pitonyak 4/7/17.</li> <li>5. Final CAT paper submitted to Dr. Watling 4/26/17.</li> </ol>

Meet with Dr. Leanna Birge (Added after submission of Implementation Plan)	4/26/17	1. Schedule a meeting with Dr. Birge by 4/26/17.
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### Outcomes

We plan to survey UW students and Dr. Birge to determine how and to what extent information from our CAT was implemented in their survey, educational video, and grant writing. This survey will contain Likert rating scales (strongly agree to strongly disagree), as well as open-ended questions to discern the true usefulness of our data.

If time allowed, we could implement additional outcome measures to determine the effectiveness of our more far reaching knowledge translation plans. This could include surveying practitioners who read the column article to better understand how it affected their daily practice. Important data could be gleaned through this survey as this journal reaches therapists across the country, many of whom may be community therapists who play a pivotal role in encouraging their clients to attend NFU programs. Another hypothetical, future outcome measure would be surveying Dr. Tanta and her staff to understand how or if our CAT table has affected their practice and client attendance rates.

### **The Knowledge Translation Process**

We conducted three knowledge translation activities: intra-professional collaboration with UW occupational therapy students, collaboration with grant writer Dr. Birge, and submission of an article to the *Journal of Occupational Therapy Schools and Early Intervention*. Due to the unique nature of each activity and unforeseen difficulties, respective outcomes varied.

The initial plan for intra-professional collaboration with the UW OT students was to have a meeting to discuss both of our projects and findings up to that point and then determine how our research could inform the development of their project. Their project was to complete a literature review of research regarding the experiences of parents and infants in the NICU, NICU outcomes, and barriers to care as well as to create a script for an informational video about the NFU program at VMC that would be presented to families before discharge. While the meeting was informative, by the time we spoke with the UW students they had already completed their project and did not require any further information. Due to this unforeseen setback with this knowledge translation activity, we were unable to produce any tangible outcomes to monitor. We had initially planned to survey the UW students to determine how our research informed their project, but ultimately, we did not administer a survey and instead sought alternative options for knowledge translation.

After discussion with Dr. Watling, who encouraged us to find other avenues to apply our research, we reached out to Dr. Tanta to determine her needs for knowledge translation. She recommended that we set up a meeting with VMC's new grant writer, Dr. Birge, to provide her with information that could be incorporated into a new grant to raise funding for the NFU program. After initial email introductions and identification of a suitable date, we conducted a

group telephone conference. Dr. Birge was well prepared, having thoroughly reviewed our CAT table and all articles referenced. Specifically, she wanted to know the best evidence-based options to implement at VMC to improve NFU attendance. Although we did not conduct a formal survey outcome measure with Dr. Birge, we did ask if she found our research and conversation to be helpful. She stated that our research would be used to implement brief QI studies to support her grant requests with concrete data.

Lastly, to complete the article submission process, we met with Dr. Swinth, the editor of the *Journal of Occupational Therapy, Schools, and Early Intervention*. She provided us with copies of previous articles published by prior students to understand how to format our paper to meet the journal's criteria. We submitted an article draft to Dr. Tanta for her review and she suggested we add an introduction and emphasize the implications for occupational therapy practitioners. After incorporating her feedback into our article, we submitted it to Dr. Tanta again. She approved the article and will submit it for publication in her monthly column. The timeline for approval and publication in the journal reaches beyond the time constraints of this project, limiting our ability to monitor outcomes of the article. Additionally, it would be difficult to survey readers of the article because it is unclear who would read the article or who might utilize the information to inform their practice.

### **Knowledge Translation Product: Submitted Article to Journal**

Facilitators and Barriers to Neonatal Intensive Care Unit Follow-Up Program Attendance: A  
Critically Appraised Topic

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**Abstract:** NICU follow-up (NFU) programs often experience low service utilization rates. Attendance to follow-up appointments is vital for both the health outcomes of the infants and to ensure continued funding for these programs. This literature review examines factors that may act as facilitators or barriers to NFU attendance. Occupational therapists who treat NICU graduates, both hospital and community based, would benefit from considering these factors to facilitate increased access to follow-up services.

#### **Introduction**

Not only do neonatal intensive care units (NICU) provide inpatient services, they also offer post-discharge, outpatient follow-up services. NICU follow-up (NFU) programs offer a variety of services from a multi-disciplinary team including, but not limited to, screening for developmental delays, assessment, diagnosis, referral to therapy services, coordination of care, and parent education and support (Ballantyne, Stevens, Guttman, Willan, & Rosenbaum, 2012). These programs provide holistic and optimized care that can lead to better outcomes for these infants who are at risk for developmental delays and a number of short term and long term health problems (Nehra, Pici, Visintainer, & Kase, 2009; Harmon, Conaway, Sinkin, & Blackman, 2013). Utilization of NFU services is essential considering a number of studies have found early detection and intervention is associated with better developmental outcomes for these infants (Nehra et al, 2009; Harmon et al, 2013). The issue at hand is the insufficient utilization of NFU program services. It is well documented that NFU appointment attendance rates are less than optimal (Ballantyne et al, 2012; Nehra et al, 2009; Harmon et al, 2013). It is in the best interest of the consumers and providers to ensure the highest access possible. Thus, investigations as to the facilitators and barriers to attending NFU services are necessary for providers to determine what measures they can take to increase access to their programs. This paper is a summary of the current literature available that has researched this issue.

#### **Inclusion and Exclusion Criteria**

Inclusion criteria limited the research peer reviewed articles addressing NICU follow-up and/or outpatient services, as well as articles discussing barriers or facilitators to utilization of such services. Excluded articles did not address NICU follow-up or outpatient services.

#### **Databases Searched**

Databases searched included PubMed, Medline, CINAHL, OT Search, Cochrane library, ProQuest, Primo, Psycinfo, Google Scholar, and Nursing and Allied Health Database.

**Table 1. Search Strategy**

Categories	Key Search Terms
Patient/Client Population	Families, infants, neona*, prematur*
Intervention (Assessment)	NICU, neonatal intensive care unit, developmental AND Follow-up, follow-up program, occupational therapy, physical therapy, post-discharge
Comparison	Barriers, facilita*, promote, discourage, encourage, inhibit*
Outcomes	Attendance, adherence, participation, developmental outcomes, quality of life, well-being

**Table 2. Summary of Study Designs of Articles Selected for Appraisal**

Level of Evidence	Study Design/Methodology	Number of Articles Selected
I	Systematic reviews, meta-analysis, randomized controlled trials	3
II	Two groups, nonrandomized studies (e.g., cohort, case-control)	4
III	One group, nonrandomized (e.g., before and after, pretest, and posttest)	1
IV	Descriptive studies that include analysis of outcomes (single subject design, case series)	7
V	Case reports and expert opinion, which include narrative literature reviews and consensus statements See Tables 4-6 in Final CAT Paper	2

See Tables 4-6 in Final CAT Paper for CAT Table

## Implications

### *Implications for Consumers:*

The consumers for the NFU services are infants who have been discharged from the NICU and their parents or guardians. The research indicates that the benefits to attending a NFU program include improved developmental outcomes and often increased access to therapy services via a bridge between the NICU and Early Intervention services. Although demographic barriers and contextual factors such as high stress levels or lack of social support

can make attendance difficult, consumers should be aware of the improved developmental outcomes due to NFU attendance. Consumers should demand education and appropriate services to understand the benefits of attending and utilizing the NFU program. Most importantly, providers should be advocates and take the necessary steps to ensure consumer access.

### ***Implications for Practitioners:***

The results of this research have implications for all practitioners involved in NICU follow-up programs, including nurses, doctors, occupational therapists, physical therapists, speech language pathologists, and others. These multidisciplinary teams share the common goal of ensuring infants being discharged from the NICU are returning for follow-up appointments in order to assess their health and development. Identifying the factors influencing why families would not be utilizing follow-up services is the first step in implementing program changes that would increase service utilization. Based on the factors identified, the literature provided a variety of suggestions for increasing NICU follow-up service utilization. Suggestions related to appointment scheduling include: scheduling all follow-up appointments before discharge, giving multiple chances to make appointments, scheduling appointments later in the day, having a social worker or coordinator meet with and discuss discharge plan with families, providing appointment reminder cards, providing a “baby” letter, and/or calling or sending reminder letters. Suggestions related to client education and support included: ensuring families understand the importance and need for attending follow-up services, providing education in multiple modalities, and providing a “foster grandmother” to families. Suggestions related to environmental factors included: providing transportation to/from clinic, having a mobile clinic, and utilizing telemedicine. These suggestions may augment standard NFU protocols to mitigate the common factors leading to decreased attendance, maximizing utilization of services.

### ***Implications for Researchers:***

Future research should include high rigor quantitative and qualitative design, investigating complex factors such as substance abuse, psychiatric conditions, or English as a second language, as they were frequently cited as exclusion criteria. Researchers should elaborate on why parents cannot or do not want to attend NFU by analyzing various systems and their dynamic interactions that may affect attendance (i.e. social, cultural, environmental).

### ***Bottom Line for Occupational Therapy Practice/ Recommendations for Better Practice:***

Based upon the current literature, occupational therapists can advocate for their follow-up programs and implement these suggestions to increase NFU attendance rates. Therapeutic use of self and building a strong rapport are crucial factors in increasing attendance. Occupational therapists should be aware of factors that put individual consumers at higher risk for non-attendance and take action to provide equitable care. Therapists can advocate for provided transportation or emphasize the need to schedule appointments for the follow-up program prior to NICU discharge. Therapists can encourage team building to ensure a multidisciplinary approach and advocate for utilization of a coordinator to ensure a continuum

of care. Occupational therapists have a unique understanding of the dynamic roles played by family members and can create targeted support groups to increase attendance for at-risk consumers.

See pages 31-33 for CAT Table References.

### Outline of Implementation Plan Progress

**Table 1. Tasks/Products Scheduled Interim Dates of Completion**

<b>Task/Product (1a-f above)</b>	<b>Deadline Date</b>	<b>Steps w/ Dates to achieve the final outcome</b>	<b>Progress</b>
<p>Column Article in <i>Journal of Occupational Therapy, Schools, and Early Intervention</i></p>	4/14/17	<ol style="list-style-type: none"> <li>1. Meet with Dr. Swinth to review journal articles with previously published CAT data. 2/23/17.</li> <li>2. Write first draft of article by and group peer edit. 2/27/17.</li> <li>3. Have draft submitted to Dr. Swinth, Dr. Pitonyak, and/or Dr. Watling by 3/6/17</li> <li>4. Make a final draft by 3/20/17</li> <li>5. Have final draft looked at by Dr. Tanta 4/03/17</li> <li>6. Submit to Dr. Tanta by 4/14/17</li> </ol>	<ol style="list-style-type: none"> <li>1. Met with Dr. Swinth and borrowed hard copy journals 3/1/17.</li> <li>2. First draft written collaboratively, no group peer edit, 3/13/17.</li> <li>3. Students did not submit draft to Dr. Pitonyak or Dr. Watling as it was determined Dr. Tanta would be the only reviewer.</li> <li>4. Final draft completed 4/4/17.</li> <li>5. Final draft emailed to Dr. Tanta 4/4/17.</li> <li>6. Final article emailed to Dr. Tanta 4/10/17.</li> </ol>
<p>Meet with UW Students, provide brief paper to summarize the interaction and how the KT process went. Assist with formulating client survey questions.</p>	4/26/17	<ol style="list-style-type: none"> <li>1. Email UW students to set up time to meet time 2/17/17.</li> <li>2. Per UW availability, plan to meet prior to 3/10/17. Draft reflections on intra-professional collaboration.</li> <li>3. Schedule meeting with Dr. Watling and Dr. Pitonyak to go over UW</li> </ol>	<ol style="list-style-type: none"> <li>1. Emailed UW students 3/1/17 after KT discussion with Dr. Tanta.</li> <li>2. Phone conference with UW students 3/8/17.</li> <li>3. Emailed Dr. Watling and Dr. Tanta regarding collaboration with UW students 3/8/17.</li> <li>4. Emailed Dr. Tanta 3/9/17 to suggest creating a handout for her staff.</li> <li>5. Dr. Tanta responded</li> </ol>

		collaboration by 3/24/17. 4. Submit draft to Dr. Pitonyak 4/7/17. 5. Final CAT paper submitted to Dr. Watling 4/26/17.	with idea to work with grant writer 3/20/17.
Present research to Dr. Birge to support her role in the NFU clinic.	4/26/17	There was no plan in place for this due to late addition of this idea. Actual dates are listed to the right.	1. Confirmed grant writer collaboration with Dr. Watling 3/22/17. 2. Dr. Tanta introduced students to Leanna Birge 3/26/17. 3. Students complete teleconference with Dr. Birge 4/6/17.

### Knowledge Translation Outcome Monitoring

Due to the unique nature of our knowledge translation activities it was difficult to monitor and determine outcomes. We had planned to survey the UW students to assess the usefulness of the information we had provided. However, due to the difference in schedule between semesters at UPS and quarters at UW, they had already completed their literature review and project for Dr. Tanta. Thus, our research did not influence their work. Additionally, upon exchange of material between the UPS and UW students, it was clear that the actual practical implications of each research project were very different and did not overlap to a significant extent. Therefore, it was deemed unnecessary to distribute a survey to them, and we instead facilitated a discussion as to what they thought of our research and if they thought it would have influenced the approach they took to their project.

We decided not to monitor submission of our article due to the lengthy timeline for approval and publication. In addition, the challenge of identifying and randomly surveying

potential article readers prevented us from monitoring this outcome, although it can be assumed that the article will have some effect on readers.

Regarding the meeting with Dr. Birge, we again were unable to conduct a formal outcome measure due to the timing conflicts with the completion of the grant and the deadlines for this project. Instead, at the end of the teleconference, we asked how our research might have been of value to her. She indicated that common, effective themes that emerged from the research would be integrated into the clinic and her grant writing. Although not a formal outcome measure, Dr. Birge clearly communicated how valuable the research was in providing foundational knowledge and future considerations.

### **Effectiveness of the Knowledge Translation Activities**

As previously stated, due to the unique nature of the knowledge translation activities we conducted and the limited options for outcomes monitoring, it is difficult to quantify the effect of these activities. Regarding the intra-professional collaboration with the UW students, our initial intentions to assist them with the development of their project did not pan out due to differences in school schedules. They indicated that our research would have helped guide them during their literature review, however it was not significantly applicable to their project. Thus, the UW students, having already completed their literature review and project, did not benefit significantly from the information we provided. However, it was beneficial to participate in intra-professional collaboration, engage in a dialogue about complementary research, and experience firsthand the importance of compatible schedules during research collaborations. Additionally, it was valuable to learn about the research project and products the UW students created. Although we had more depth to our focused research question, they had far more breadth focusing on NICUs and NFU programs as a whole.

Again, although we were unable to monitor any outcomes of the article we submitted for publication, we feel that if published in the *Journal of Occupational Therapy, Schools, and Early Intervention*, it will increase awareness among pediatric practitioners of the factors influencing NFU service utilization and will highlight the need for further research on the topic. The article highlights important barriers and facilitators of which therapists should be aware so that they can adjust their practice to best support clients and their families. Thus, it may help both hospital and community based practitioners understand their client population and identify methods for increasing access to and/or attendance to NFU services. Due to ease of accessibility and archiving of articles, this article has the potential to reach many readers over time, extending the influence of our research.

Finally, we reached similar conclusions regarding the collaboration with Dr. Birge. Unable to conduct a formal outcome monitoring process, the effectiveness of our knowledge translation is based on Dr. Birge's report at the end of the meeting. Dr. Birge stated that, based on the research we presented her, the clinic would implement informal QI projects. These projects would demonstrate the effectiveness of the research in clinic and provide additional support for grant funding. Thus, our research supports Dr. Birge's attempts to seek grant funding for the NFU program as the grants were mainly focused on supporting new research related to the CAT review. In addition, our informational collaboration with Dr. Birge was highly effective in helping her identify specific facilitators to NFU attendance. Through the QI studies, she may receive funding to support a care coordinator/social worker and improved transportation options as we had suggested. Additionally, this contributes to research that will fill current gaps in knowledge related to efficacy of NFU programs.

### Process Analysis

The process of creating a CAT review and conducting knowledge translation activities involved 1) identifying an information gap within a practice area, 2) establishing search criteria and combing through all available literature on the identified topic, 3) analyzing and outlining the literature found to determine implications, 4) creating and conducting knowledge translation activities, and 5) measuring the outcomes of those activities. Overall, this process presented with both challenges and valuable learning opportunities.

The first challenge arose during the research portion of the process. We quickly realized that while our question is important, it has a narrow scope and there has been little research done on the topic. The lack of information available supported Dr. Tanta's suspicions about the current climate of NFU programs and made it challenging to find articles that met our search criteria. Ultimately, we determined there is still a major need for research on this topic. Despite this, Dr. Tanta was pleased with what we found and assured us that, at the least, it is beneficial for her to have concrete research to vindicate what they see in practice.

The second major challenge arose during the knowledge translation phase of the process. Initially, we presented Dr. Tanta with a number of ideas for applying our research to practice. However, due to systemic and structural constraints, none were feasible due to systemic barriers and within a reasonable timeframe. Thus, Dr. Tanta proposed a few options including collaboration with her UW student group and VMC grant writer and creation of an article for her column in *Journal of Occupational Therapy, Schools, and Early Intervention*. This led to the third major challenge, related to the outcome monitoring of the knowledge translation activities. The intra-professional collaboration with the UW students was not able to be completed as planned due to differences in project timelines. Similarly, while the submission of an article and

the meeting with Dr. Birge was successful, we were unable to monitor outcomes due to time constraints and logistical issues. However, informal interview of Dr. Birge revealed that our research will likely be of value to her efforts and thus indicates some level of success in translating the valuable knowledge we gathered.

Overall, this process has been a learning experience on various levels. We learned how to complete a literature search, write a critical analysis of topic (CAT), and synthesize meaningful implications. We also learned to integrate feedback from various sources throughout creation of our project. Our collaborating clinician, Dr. Tanta, was supportive throughout the process, receptive to research findings, and determined to find valuable KT products. On a personal level, understanding the factors that affect NFU program attendance has contributed to our therapeutic use of self as we learn about client/family factors such as parental stress and specific stress management styles.

### **Recommendations for Future Projects**

Due to some of the challenges faced when researching this topic, we believe there is little opportunity for future follow-on projects. After identifying the factors influencing attendance to NFU appointments, the logical next step would be to investigate specific strategies for increasing access to and utilization of NFU services. However, this is difficult as there is even less research available regarding that topic than there was to answer our original question. Another option could be to research NFU program outcomes in order to justify the continuation of follow-up services, which, due to poor service utilization by consumers, is in jeopardy of losing funding. However, another challenge to following up on this topic is the limited opportunity to advance occupational therapy practice specifically. This topic applies to OT practice only on a superficial level in that OTs are part of the multidisciplinary team working in these programs. OTs have the

potential to take the lead in improving these programs, however being a specialty practice area, this research applies only to a small group of practitioners. Thus, there is limited opportunity to apply findings on this topic to general OT practice.

Working with Dr. Tanta was a wonderful and rewarding experience, therefore our group suggests that there may be other questions that Dr. Tanta needs answered regarding her pediatric practice as a whole. Though NFU programs may not be a good future CAT topic, Dr. Tanta oversees many things as a rehabilitation director and likely has many other topics worth researching. For example, she could have students explore the different models for service delivery for children discharged from the NICU, such as primary care models or EI models.

**References not listed in CAT table**

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### **Acknowledgements**

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