THE EARLY SUPPORT PROGRAM TO HELP ESTABLISH BONDING BETWEEN MOTHERS AND THEIR NEWBORNS WITH DOWN SYNDROME: EVIDENCE-BASED NURSING

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ABSTRACT

This thematic paper aimed at summarizing current evidence about nursing intervention and significant advice for promoting bonding between mothers and their newborns with Down syndrome at Kurigram Sadar Hospital, Bangladesh. The method of study included searching electronic databases for intervention recommendations using PICO framework, appraising the validity and strength of the evidence, and synthesizing the evidence. Five research and review articles (including one systematic review, one controlled trial without randomization, one guideline, and two review articles) were selected to be included as evidence in this study. The significant findings from the reviewed evidence were adjusted for use in a clinical context in Bangladesh.

The recommendations for practice including proper timing to inform the diagnosis, psychological support relevant to the stage of acceptance of the baby with Down syndrome, early and subsequent skin-to-skin care and breastfeeding, discouragement of swaddling, facilitation of rooming-in are proposed. Certain in-service and short course training programs designed for Bangladeshi nurses at Kurigram Sadar Hospital to improve their competency needed for providing support to the mothers and families of Down syndrome children are also suggested.

KEY WORDS: BONDING/ DOWN SYNDROME/ EARLY SUPPORT PROGRAM/ EVIDENCE-BASED NURSING.

36 pages

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CHEPTER I
INTRODUCTION

1.1 Background and Significance of the Clinical Problem

Down syndrome is the most common chromosomal abnormality that is a result of the presence of an extra 21st chromosome. It is commonly diagnosed in the immediate newborn period. Down syndrome causes developmental disabilities, mental handicap, and also is susceptible to various health problems, for example, congenital heart disease, gastrointestinal malformations, and respiratory infections (Lam, & Mackenzie, 2002). Children with Down syndrome have a widely recognized characteristic appearance. Their heads may be smaller than normal and abnormally shaped. Other noticeable characteristics of Down syndrome are: flat nasal bridge, protruding tongue, upward slanting eyes, small mouth, small ears, excessive skin at the nape of the neck, short hands and fingers, and a single crease in the palm (Bull & Committee on Genetics, 2011). The incidence rate of Down syndrome in a developed country such as the United States, is approximately 14.47/10,000 births (McGrath, Stransky, Cooley, & Moeschler, 2011). Down Syndrome Education International (2014), a leading international charity in the United Kingdom, estimates that Down syndrome affects between 1 in 1,500 and 1 in 400 babies born in different countries, or 220,000 annually, worldwide. For a developing country, Bangladesh in particular, there is no elicit evidence based data. The best available information in Bangladesh is from an unpublished survey report from the Ministry of Social Welfare in 2005, which indicated that, there were 45,680 children with disabilities who needed support in primary schools and among them were significant number of students with intellectual disabilities (Hossain, 2007).

A normal and healthy baby born is extremely expected by a mother who brings the most joyfulness to the whole family. In contrast, the birth of an infant with Down syndrome is often perceived as the loss of a healthy baby; and the mother may experience self-blame for this abnormality (Wright, 2008). The mothers of children

with Down syndrome often face this unexpected event with a traumatic crisis reaction and need considerable support (Hedov,Wikblad, &Anneren, 2002). They experience a great deal of uncertainty following the birth of the Down syndrome. For example, how does this situation affect their family? how could the child be cured or treated? how would the child's future be? and so on. A qualitative study of the experience of Chinese mothers having Down syndrome children revealed that the mothers were in shock immediately after being informed of the incurable learning disability, Down syndrome, of the child (Lam & Mackenzie, 2002). Lam and Mackenzie also found that some mothers could accept the child and adapt themselves to this crisis while some could not. The mothers who could not accept their children were intentionally neglectful for the provision of proper childcare. The study also indicated that the mothers worried about the child's future and had insufficient knowledge about how to care for the child with this syndrome. Another qualitative study by Chang and Hsu (2007) revealed that the mothers with learning disabled children (such as Down syndrome) fell in a sense of sorrow and avoided to discuss with their spouses about fears and concerns; and concern about the child's future was the most frequently stressful experience for them. In addition, this study also indicated that the formal professional support and good services were not available in their community. A qualitative study from India, a neighbor country of Bangladesh, conducted by Reeja and Sujatha (2013) also revealed that birth of a child with Down syndrome could produce the following perceptions and changes: feeling shock and depressed with non-acceptance of the birth of a Down syndrome child, changes of lifestyle due to more demanding and complex situation of having a disabled child, and worried about the child's uncertain future. Reeja and Sujatha also found the positive sides of having a Down syndrome child; that is, acceptance and support from community, and positiveness towards life. However, such positiveness come later in life after encountering the adverse feelings and situations.

Behavioral capacities of normal neonates are amazing; they see, hear, and move in rhythm with their mothers' voice in the first minutes and hours of life resulting in a beautiful synchronous relationship (Klaus & Kennel, 1982). Even though the newborn babies are far more competent, social, and responsive, they can only be competent in the context of a relationship (Malekpour, 2007). Put in other words, a

newborn baby is born expecting a competent mother/caregiver to pay attention to and care for him or her. Even a healthy newborn needs his/her mother to initiate and fulfil the context of relationship, a Down syndrome baby needs much more of it. If the warm context is not early promoted, the situation will get worse when the child grows up. The shocking situation of having a Down syndrome baby may deteriorate maternal-infant synchrony, or matched behavior and biological rhythms between a mother and infant which occurs in short, intense, and playful interactions (Baker & McGrath, 2011). Synchronous relationships help the mother to feel confident with her maternal role which, in turn, will influence the child language development, self-regulation, attachment, and successful development of future social relationship (Baker & McGrath, 2011). In contrast, if the mother has difficulty in reading and interpreting infant cues, she will feel anxious, depressed, and less competent to be a mother. These feelings could result in emotionally harmful parenting which will affect the child later development. With unexpected birth of Down syndrome, a mother may be less competent to function the maternal role in particular to establish proper bonding and affective ties from mother to baby. Together with the aforementioned deficits of the child, there will be less turn-taking and less effective communication leading to parental perception of declined approachability. This may have harmful effect on mother-child relationship.

Bonding is the establishment of a shared emotional and psychological closeness between a mother (or primary caregivers) and her newborn baby. It reflects the affection feelings of parents toward the newborn. Usually, a mother starts forming or establishing bonding with her baby when she realizes that she is getting pregnant. Until the birth of the baby, there is a sensitive period in the first minutes and hours of life which is essential that the mother has close contact with her newborn baby for later development to be optimal, according to Klaus and Kennell (1982). A firm bond between mother and baby is a good start for their relationship. When mother and baby have frequent time together, the mother learns to recognize her baby’s needs, responding tenderly and lovingly (Crenshaw, 2004). Previous studies have also revealed that bonding and early interaction influence the growth and organization of the maturing brain, critically affecting both physiological and psychological

development (Mantymaa et al., 2003). Thus, if there is any interruption of bonding, later development of the child may be harmful.

To establish maternal-infant bonding, certain supports are needed. Placing the newborn baby skin-to-skin on the mother's chest (Kangaroo care), promoting early and frequently breastfeeding, and discouraging mother-infant separation are essential early supports that nurses should provide for the mother-infant dyads to initiate the bonding process (Johnson, 2013). The Kangaroo care method facilitates more positive feelings of the mothers towards their infants and more maternal sensitivity, increases sense of maternal roles, and reduces parental stress and depression. Also, this method helps increase infant movement towards their mother during feeding (Tallandini & Scalembra, 2006). During breastfeeding, closeness between mother and infant helps increase affectionate behaviors and interaction. In the meantime, oxytocin, which is related to delivery, lactation, mood regulation, sexual functioning and parenting behavior (Feldman, Weller, Zagoory-Sharon, & Levine, 2007), facilitates an emotional bonding by reducing maternal anxiety (Galbally, Lewis, Ijzendoorn, & Permezel, 2011).

The establishment of bonding needs engagement from both mother and baby. In a case of Down syndrome, the baby's behavioral capacities and the mother's formulation of bonding and affective ties are questionable. Particularly, the mother who is the key person to start creating a warm relationship with the baby may not be ready to perform such role. According to Klaus and Kennell (1982), and Jimenez, Cordero, Ferre, Lopez, & Jimenez (2012), parents of babies with Down syndrome go through five stages after knowing the diagnosis of their children including: **impact stage** - getting shock with the diagnosis; **denial stage** - showing a tendency to deny the reality; **sadness and pain stage** - feeling sad and painful with remaining worried and fearful of the future; **adaptation stage** - managing to accept their feeling and the child's condition; **reorganization stage** – assuming a different attitude by accepting the baby as part of the family and helping in its rehabilitation. In case of mother and newborn with Down syndrome, bonding or attachment from mother to newborn may be interrupted during early hours of life or a sensitive period. During hospital stay of both mother and Down syndrome baby, the mother is usually in a shock stage and not able to be sufficiently sensitive and responsive to the neonate. Consequently,

maternal-infant synchrony is difficult to develop resulting in poor maternal-infant interaction. Thus, a support for establishing maternal-infant bonding must be provided to both the mother and her infant at early stage (or as soon as possible after birth and being informed of Down syndrome).

Despite the need of early support for establishing bonding among the mothers and their newborns with Down syndrome, few bonding interventions were found from the literature review. Most early intervention programs have focused on stimulating the development of children with Down syndrome. Hines and Bennett (1996) reviewed studies evaluating the effectiveness of early intervention for children with Down syndrome. The findings revealed the positive changes in the development of children who were exposed to early intervention programs. Hines and Bennett found that parent involvement was a significant component of those programs. Their review provided evidence in support of the notion that quality bonding during the early hours of Down syndrome newborns' lives is essential for mother-infant relationship and later child development.

In Bangladesh, due to lack of diagnostic test for Down syndrome during pregnancy, almost all of the mothers are informed of this chromosome abnormality after the birth of the child. As a Bangladeshi nurse, the author has often experienced the reactions of mothers who are informed about the Down syndrome of their babies. Their expectation of having a 'perfect' child is suddenly collapsed. The stages of shock and denial usually happen immediately after the birth of the child. Most of them feel like being fallen down from sky to soils, get disappointed, refuse to accept the babies from the very beginning, and get angry. As most mothers are Muslim, they view this crisis as Allah's will that they must bitterly accept. Some also believe that the birth of a disabled child results from heaven's punishment for their ancestor's wrongdoing. During this problematic time, the mothers and the babies still stay in hospital and, in fact, the babies are rooming-in (the baby's crib is kept by the side of the mother's bed). If the process of bonding and affective ties is interrupted during a sensitive period (early hours of the child' s life), the mother and her Down syndrome baby will get back to home without sufficiently forming bonding and affective ties. The environment of care from such reactions, perceptions, and beliefs of the mothers exposes the children to the risk of lacking maternal-infant synchrony resulting in being

abandoned, mistreated, and permanent dissociation, which in turn will affect the child's survival and later development (Baker & McGrath, 2011). Thus, provision of help for mothers to accept their Down syndrome babies from the very beginning and form the strong maternal-newborn bonding before discharge is essential.

1.2 Clinical Problem of the Study

Kurigram Sadar Hospital, Kurigram, Bangladesh, is a district hospital where modern technological medical and nursing services are hardly seen. Due to limited medical equipment and human resources, few pregnant mothers have a chance to obtain a diagnostic test for chromosomal abnormality like Down syndrome. Routinely, a pregnant woman will receive blood and urine checked with health supervision for herself and the fetus. Ultrasonography may be prescribed for some cases Moreover, most pregnant women do not aware of the importance of attending an antenatal clinic for the care of their pregnancy. They usually come to a hospital at the time for delivery. Thus, almost all of mothers will be informed of their baby's abnormality after birth. A doctor is usually responsible for informing the mother about the diagnosis of Down syndrome at 24-48 hours after birth. Nurses are not allowed to involve in a process of informing the diagnosis.

At Kurigram Sadar Hospital , the mothers' reactions of grief and loss for a healthy baby are not effectively managed through nursing care in a systematic way. Sympathy and comfort as well as needed information may be given to the mothers by nurses in different patterns and styles. Moreover, a specific nursing intervention for helping these grieved mothers to form affective ties with their Down syndrome baby in a proper and timely manner is not available. Routinely, all newborns are allowed to stay with their mothers in the same bed or in a crib bedside. Even though a rooming-in is one approach for mothers to learn their own babies and form the bonding, the mothers of Down syndrome need more special help in addition to the routine one. In this clinical context, the "how to" help this group of mothers establish proper bonding with their Down syndrome baby is a major clinical concern. As a nurse who has a crucial role to help and strengthen bonding between the mother and her child from the time Down syndrome is diagnosed, the author is interested in determining the

recommendations about essential nursing care activities and significant concerns for promoting bonding between mothers and their newborns with Down syndrome. The findings from this study are expected to be the preliminary evidence-based information for the further development of the early support program that helps mothers establish bonding with their Down syndrome baby during the early hours after birth, which will positively affect the later maternal-infant synchrony and development of the child.

1.3 Purpose of the Study

The purpose of this study was to summarize current evidence about nursing intervention and significant advice for promoting bonding between mothers and their newborns with Down syndrome.

1.4 Expected Benefit of the Study

Since there has not been any formal nursing intervention in Kurigram Sadar Hospital, Bangladesh, to help the mothers whose newborn babies are diagnosed with Down syndrome, the findings from this study will serve as a recommendation of nursing practice for nurses in supporting mothers to form quality and timely bonding to their Down syndrome babies.

Moreover, the findings from this study will provide the preliminary evidence-based information for the further development of the early support program that helps mothers establish bonding with their Down syndrome baby during the early hours after birth, which will positively affect the later maternal-infant synchrony and development of the child. Also, this study would provide a basis to future research in this area.

CHAPTER II
METHODOLOGY

2.1 Search Strategy

The articles included in this review were obtained through a systematic search of published research available from 2000 to 2014.

Search framework

The author searched and selected evidence for early support program to help establish bonding between mothers and their newborns with Down syndrome by using the PICO Framework, a method of putting together a search strategy that allowed the author to take a more evidence based approach to the literature searching when searching bibliographic databases (Melnyk & Fineout-Overholt, 2011), with the following details:

P (Population)	=	mothers with Down syndrome newborns
I (Intervention)	=	establishment of maternal-infant bonding
C (Comparison)	=	usual activities
O (Outcome)	=	maternal-infant bonding

Scope of searching

The early support program to help establish bonding between mothers and their newborns with Down syndrome based on validated evidence-based practice was searched from the following scope:

1) Keywords used in the search according to the PICO framework.

The author also broadened the search by thinking about synonyms and other keywords that could be used to make sure that any important research were not missed. An extended PICO search strategy resulted in another keywords as follows:

P (Population)	=	Down syndrome, developmental disability, Intellectual disability

I (Intervention)	=	support program, early intervention
C (Comparison)	=	usual activities
O (Outcome)	=	bonding, affective ties, mother-infant relationship, attachment

The search used a Boolean operator (AND, OR) as conjunctions to combine keywords in a search, resulting in more focused and productive results. For each PICO element, the author collected any synonyms by linking terms with “OR”, then located citations that are relevant to all the PICO elements by linking with “AND”.

2) The databases/sources used for the search:

The author used electronic databases/sources subscribed by Mahidol University Library and Faculty of Nursing Library to service their community. The selected data bases of published journal to search full-text journal articles included:

- Cochrane Database of Systematic Reviews
- Joanna Briggs Institute Systematic Reviews Database.
- Cumulative Index to Nursing and Allied Health (CINAHL),
- Ovid Full Text,
- ProQuest Nursing and Allied Health Source, and
- PubMed.

These databases were used to search for single research studies. The author also traced back the references from the journal retrieved and, then, searched further from libraries and electronic databases. For guidelines, the authors searched from National Institute for Health and Care Excellence (NICE) websites.

3) Type of evidence

The author searched for guidelines, systematic reviews of randomized controlled trials (RCTs), and high quality single randomized controlled trials acquired from full text studies published in English from 2009 to 2014. In case of no results from the searching, the author would use lower levels of evidence relevant to the clinical problem of the current study instead.

2.2 Appraisal Method and Levels of Evidence

Appraisal Method4

Upon searching the evidence, the process of critical appraisal will be performed by following Grace's (2012) guide for critical appraisal of evidence for therapy questions. The process of critical appraisal helps clinicians identify the most relevant and high quality evidence available to guide their clinical practice. As therapy questions are questions about cause and effect, thus, high level of evidence is needed. In this study, evidence in terms of systematic review of RCTs and high quality single randomized trials would be retrieved. The critical appraisal of therapy evidence is guided by a short set of questions about the validity of the results, the nature of the results, and the ways the results can be applied to patient care as follows:

1. Are the results valid?

This appraising question concerns if a change in the cause or therapy is associated with a change in the effect or outcome. The strongest research design for therapy question is clinical trials where two or more groups are formed and the researcher has control over the change in the cause/therapy for each group (Grace, 2012). What should be considered includes:

1.1 Were the groups being compared similar to each other at the start of the study?

To answer "yes" to this question, the process of random assignment must be concealed; intention-to-treat analysis should be used to ensure a fairer group comparison; there are no significant differences between the groups on the basis of other factors that could affect the outcome.

1.2 Did the groups being compared remain similar to each other, except for the therapy, during the study?

Threats to validity should assess to ensure that nothing could "go wrong" in the research. Blinding the subjects, care providers, and outcome assessors is very important.

2. What are the results?

This appraising question concerns if the effects have sufficient influence on practice, clinically and statistically. The treatment effect should be large enough to show statistically significant. In addition to the statistical meaning, the treatment effect must be precise too. That is, the treatment effect should be in the estimated range when the study are repeated with similar participants.

3. How can the results be applied to patient care?

This appraising question concerns if the findings are relevant to their own practice situations. What should be considered includes:

3.1 Were the study patients similar to the patients in my care?

This question is asking about the generalizability of the study. Thus, we must be sure that our patients match the study inclusion criteria.

3.2 Were all the clinically important outcomes considered?

All clinically important desirable and undesirable outcomes related to the therapy must be determined. Not only primary outcome (or intended outcome), but also secondary outcome (those other effects) may be important considerations in practice.

3.3 Is this evidence worth applying in the care of my patients?

This is the clinical decision-making question. This decision depends on the aforementioned appraisals already made.

Nurses have to use their clinical expertise, their knowledge of available resources and limitations, and their knowledge of the patients' values to evidence-based practice.

Level of Evidence

Rankings for strength of evidence indicate how strong the evidence supporting the specific recommendation is. According to the hierarchy of evidence as shown below (Melnyk & Fineout-Overholt, 2011), the highest rankings go to recommendations supported by a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines. The lowest rankings are recommendations based on expert clinical opinion.

Level I: Evidence from a systematic review or meta-analysis of all relevant randomized controlled trials (RCTs), or evidence-based clinical practice guidelines based on systematic reviews of RCTs

Level II: Evidence obtained from at least one well-designed controlled trials with randomization

Level III: Evidence obtained from well-designed controlled trials without randomization

Level IV: Evidence from well-designed case-control and cohort studies

Level V: Evidence from systematic reviews of descriptive and qualitative studies

Level VI: Evidence from a single descriptive or qualitative study

Level VII: Evidence from the opinion of authorities and/or reports of expert committees

CHAPTER III
FINDINGS

3.1 Search Results

After searching related articles from the selected databases with the addressed key words, the investigator obtained none of the related RCTs or systematic reviews. Most studies focus on early interventions aimed at stimulating the development of children with Down syndrome. Despite the unmet inclusion criteria for type of evidence, five interesting studies and reviews were found during the process of searching. These evidences are found to be relevant to the care for promoting bonding between mother and normal infant, and the proper time to inform a diagnosis of Down syndrome. Finally, due to the scarcity of the RCTs and systematic reviews about early support for mother-infant bonding in Down syndrome newborns, the investigator decided to use significant results or information from these five evidences for the recommendations of clinical practice. The key words for searching, sources of database, number of papers retrieved were shown in a below diagram. Searched papers and their level of evidence were presented in Table 3.1.

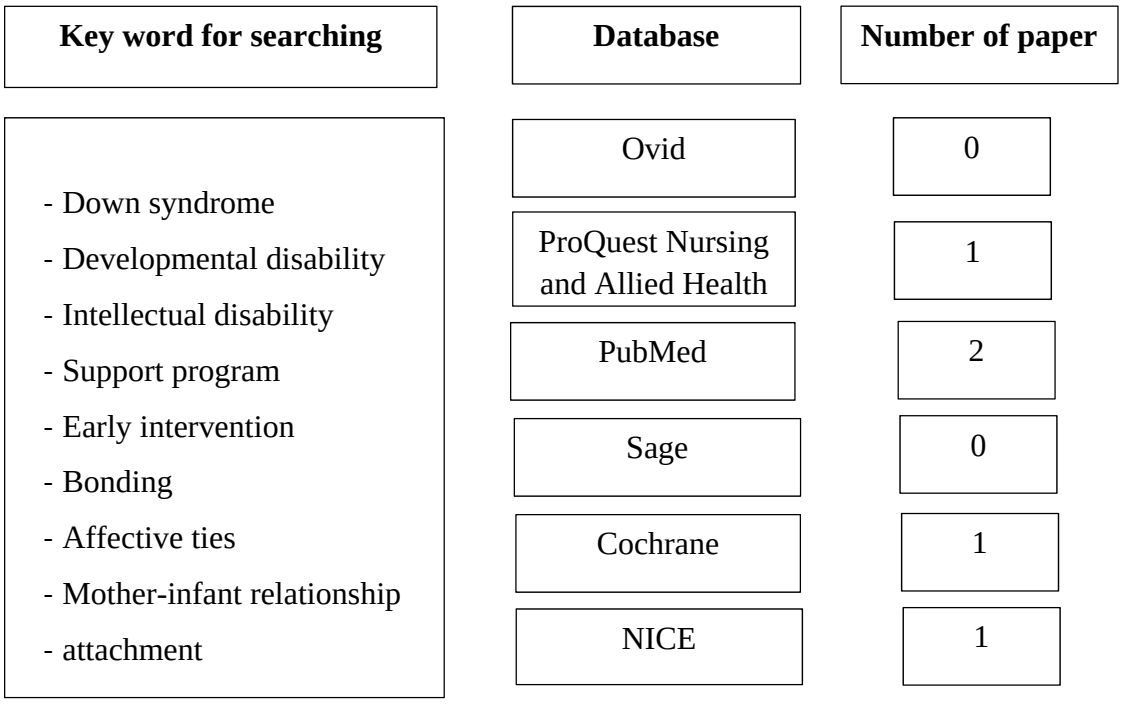

Figure 3.1 Diagram illustrating sources of evidences reviewed

Table 3.1 Searched evidence and level of evidence

Number	Searched Evidence	Design	Level of Evidence
1	Moore E. R., Anderson G. C., Bergman, N., & Dowswell, T. (2012). Early skin-to-skin contact for mothers and their healthy newborn infants. Cochrane Database of Systematic Reviews, Issue 5. Art. No. CD..3519. DOI: 10.1002/14651858.CH003519.pub3.	Systematic review	I

Table 3.1 Searched evidence and level of evidence (cont.)

Number	Searched Evidence	Design	Level of Evidence
2	Hedov, G., Wikblad, K., & Anneren, G., (2002). First information and support provided to parents of children with Down syndrome in Sweden: Clinical goals and parental experiences. *Acta Paediatrica, 91*(12), 1344-1349.	A single descriptive study	VI
3	Jimenez, E. G., Cordero, M. J. A., Ferre, J. A., Lopez, C. A. P., & Jimenez, M. C. G. (2012). Nursing intervention protocol to help establish affective ties between the newborn infant with Down's syndrome and his/her family. *International Medical Review on Down Syndrome, 16*(1), 11-16.	Experts' opinion	VII
4	National Collaborating Centre for Primary Care. (2006). *NICE clinical guideline 37: Routine postnatal care of women and their babies.* London: National Institute for Health and Clinical Excellence. Retrieve from www.nice.org.uk/CG037	An evidence-based practice guideline	I
5	Bystrova, K. et al. (2009). Early contact versus separation: Effects on mother-infant interaction one year later. *Birth, 36*(2), 97-109.	Experiment research	II

Evidence I

Title: Early skin-to-skin contact for mothers and their healthy newborn infants.

Author: Moore E. R., Anderson G. C., Bergman, N., & Dowswell, T.

Publication source: Cochrane Database of Systematic Reviews 2012, Issue 5. Art. No. CD..3519. DOI: 10.1002/14651858.CH003519.pub3.

Summary

Background: The practice of placing naked babies on their mother's bare chest at birth, so called 'skin-to-skin contact' has been conducted for long times. Currently, such practice is not performed in some cultures and hospitals in spite of its well-known benefits. Maternal and infant outcomes of skin-to-skin contact need to be confirmed.

Objective: The objective of this systematic review was to assess the effects of early skin-to-skin contact (SSC) for healthy newborn infants compared to usual hospital care (such as being held swaddled or dressed in the mothers' arms, placed in open cribs or under radiant warmers) on breastfeeding, infant physiological a, and maternal-infant bonding.

Methods: Electronic and hand searching methods were used. Only randomized controlled trials with any language were recruited. First, the titles and abstracts of all the retrieved studies were screened. Next, the full text articles were reviewed by two review authors independently for inclusion in the review. If any disagreement happened, the discussion or consultation with a third individual would be used. At this step, the assessment of risk bias in the included studies was performed using the electronic "Risk of bias" form in RevMan 2011. Then, data from the eligible studies were extracted using an extracted data from. Lastly, the data were keyed into Review Manager software (RevMan 2011) for the analysis.

The experimental groups in the included studies had early SSC starting less than 24 hours after birth, and the controls undergoing usual hospital care. The intervention or early SSC in this review was divided into 3 subcategories: (a) **Birth SSC** - the infant was placed prone skin-to-skin on the mother's abdomen or chest during the first minute post birth. The baby was suctioned while on the mother's bare chest, and dried and covered their back with a prewarmed blanket, with or without a

cap. (b) **Very early SSC** - the naked infant, with or without a cap, was placed prone on the mother's bare chest approximately at 30 to 40 minutes post birth. The infant was covered with a blanket. (c) **Early SSC** - the naked infant, with or without a cap and diaper, was placed prone and direct ventral-to-ventral on the mother's bare chest between the breasts at anytime between one and 24 hours post birth. The infant may be covered with the mother's shirt, hospital gown, or blanket. The infants in the control groups of this review obtained such usual hospital care as being held swaddled or dressed in the mothers' arms, placed in open cribs or under radiant warmers. In this review, the subgroup analysis was not performed.

Results: The review conducted included 34 RCT studies from several countries (including Canada, Chile, Germany, Guatemala, Israel, Japan, Nepal, Poland, Russia, Taiwan, Thailand, South Africa, Spain, Sweden, US, and UK). The study subjects involved 2,177 mothers and their healthy full term or late preterm newborns. The overall methodological quality of the included studies was mixed. Many studies did not provide clear information causing the difficulty in appraisal. In addition, blinding mothers, clinical staff and outcome assessors to the treatment group was greatly difficult for this type of intervention, causing the difficulty in judging the influence of lack of blinding on the study outcomes. The interventions implemented and outcomes in the included studies were found varied in terms of the methods of SSC, starting time and duration, types of outcomes, and types of measurement.

The results from the review indicated that early SSC had statistically significant positive effects on infant crying, temperature, blood glucose, and cardio-respiratory stability. For mothers who had early SSC, they were more likely to breastfeed in the first one to four months, and tended to breastfeed longer. Maternal-infant bonding in terms of mutuality and reciprocity was significantly greater in the SSC group compared to its counterpart (MD 1.30, 95%CI 0.24 to 2.36).

Evidence appraisal

Validity of the results: As this evidence was a systematic review, the methodological quality assessment of each included studies was followed the standard procedure outlined in the Cochrane Handbook for Systematic Reviews of Interventions. Risk of bias including selection bias, performance bias, detection bias,

attrition bias, and selective reporting bias was assessed. Even though the methodological quality of the 34 included studies was mixed, it could be concluded that the results of this review was valid due to its standard procedure of the review.

Nature of the results: The group differences in the outcomes of the review were reliable. The reviewers reported the statistics from the meta-analysis using mean difference and risk ratios with 95% confidence intervals. In addition, the assessment of heterogeneity was also performed. If the average treatment effect was not clinically meaningful, the trials would not be combined. If clinical or statistical heterogeneity was detected, the random-effects would be used in meta-analysis.

Applicability: Even though the subjects in this review were mother and healthy/late preterm infant dyads, the skin-to-skin contact intervention could be applied to those dyads of mothers and Down syndrome infants. The positive effect of skin-to-skin contact on maternal-infant bonding confirms the necessity of this intervention. However, due to different clinical contexts between Bangladesh and those places in the review, the application of the intervention may need some adjustments. For example, birth SSC may not be practical in my clinical setting because a nurse must dry a baby first and hypothermia of the baby is also in concern. Thus, very early SSC may be the most possible one for my setting.

Evidence II

Title: First information and support provided to parents of children with Down syndrome in Sweden: Clinical goals and parental experiences.

Author: Hedov, G., Wikblad, K., & Anneren, G.

Publication source: Acta Paediatrica 2002, 91(12), 1344-1349.

Summary

Background: When parents of a newborn infant are first informed of Down syndrome found in their baby, they usually respond with a traumatic crisis reaction. The process of disclosing a diagnosis and provision of early support (which varied from place to place) challenge the communication competency of healthcare providers. Previous studies revealed that Swedish parents of children with Down syndrome were

less satisfied with the information and support obtained. However, how the parents are initially informed the diagnosis is limited.

Objective: This study aimed to assess the clinical goals of all 51 Swedish departments of pediatrics regarding the first information and support provided to parents of newborn infants with Down syndrome, and to compare these goals with the parents' experiences of how they were first informed about the Down syndrome diagnosis, and supported.

Methodology: The study design was a retrospective study. Ten were selected from all 51 departments of pediatrics; and a national survey using a questionnaire was conducted in these 10 clinics during the year 1992-1993. The clinical goals regarding the first information and support were not different between the 51 departments and the 10 selected departments. In 1996, the retrospective data on parents' experience of being first informed about the diagnosis and the support received were collected from 207 parents of 105 children with Down syndrome who were born between 1989 and 1993. Both fathers and mothers were given the questionnaire separately. Finally, data obtained were from 165 parents from 86 of the families data, giving a response rate of 80%. The exclusion criteria included parents of Down syndrome children with severe congenital heart malformation and parents who could not fully understand the written Swedish language. The questionnaires used in this study included the visual analogue scale and open-ended questions.

Results: The departments of pediatrics in Sweden had strong goals concerning the provision of information and support to parents of newborn children with Down syndrome. However, these goals were not fully achieved because only 30% of the parents reported that they were sufficiently informed and about 50% were well supported.

For the first information, 75% of the families were told within 24 hours. About half of the families were satisfied with the timing of the disclosure of the diagnosis; some felt they were informed too late or too soon.

At least 25% of the parents indicated dissatisfaction of 4 items: the informant's lack of basic knowledge of Down syndrome; too much negative information; a lack of written information about Down syndrome; and a lack of communication skills.

Evidence appraisal

Validity of the results: This study was not an experimental design; thus, the appraisal criteria mentioned in Chapter II could not be applied. However, the study validity in terms of internal and external validity was assessed. This was a retrospective study. When the subjects were asked to recall the situations in the past, it was very difficult to ensure the accuracy of their memory. Moreover, events that happened along the passage of time since the birth of their child up to the moment of data collection might be threats to the study's internal validity. For the external validity or generalizability of the study, while random sampling was not used, the researchers attempted to select the clinics covering all existing aspects such as from north and south, rural and urban, large university hospital and small pediatric clinics. The recruitment of subjects from multiple sources could yield the greater external validity of the study. In addition, some strategies were used to control the extraneous variables. To ensure the homogeneity of the sample, inclusion and exclusion criteria were determined; and the similarity between the population of pediatric departments and the sample was also checked.

Nature of the results: This was not an experimental design, thus, the appraisal criteria (treatment effects for outcomes measured and the precision) mentioned in Chapter II could not be applied.

Applicability: In Bangladesh, it is doctors, not nurses, who have the authority to inform the diagnosis. However, the study findings provide certain implications to clinical practice; for example, the timing of informing the parents about the diagnosis, amount of information given, frequency of information given, and more tendency of positive information given. Also the qualifications of informants is very important implying the necessity of certain in-service trainings.

Evidence III

Title: Nursing intervention protocol to help establish affective ties between the newborn infant with Down's syndrome and his/her family.

Author: Jiménez. E. G., Cordero. M. J. A., Ferre J. Á., López C.A. P., and Jiménez. M. C. G.

Publication source: International Medical Review on Down's Syndrome, 2012, 16(1):11-16.

Summary

Background: Abnormality of born infants disrupts the process of affective ties / bonding between mothers and newborns. At the very beginning, these parents refuse to accept their Down's syndrome baby. In this situation, nurses need to prepare strategies to give parents emotional support and help to establish emotional bonding from the time of diagnosis, and in the period immediately after childbirth.

Objective: The objective of this research was to develop a standardized nursing protocol that helps to establish affective ties/bonding between the Down's syndrome baby and the family.

Methods: A review of literatures was conducted. Twelve scientific studies published in Medline over a period of the last seven years were retrieved. The study interventions and results were used as a guide for developing a protocol. The protocol was finally tried out with 20 mothers of newborn babies with Down syndrome during a period of one year.

Results: This paper presented a protocol consisting of 4 parts:

1) A checklist document asking the history and information about pregnancy details, biological variables, psychosocial and economic variables, problems during pregnancy, and conditions at birth and immediate puerperium.

2) Nursing activities that should provide to mothers in each psychological stages of acceptance of the baby with Down syndrome; that is impact stage, denial stage, sadness and pain stage, adaptation stage, and reorganization stage.

3) Time table for recording skin-to-skin contact and breastfeeding that are arranged for mother and infant dyads.

4) Observational record of the investigator that is briefly described the current condition of the baby, family circumstances and the acceptance of the baby by the family, and what the investigator inform/teach the family (such as basic care, feeding, and baby behavior)

Additional suggestions to nursing staff included: helping immediate physical contact between parents and the baby through breastfeeding after

birth; giving time and opportunity for parents to overcome the difficulty times through a provision of needed information with a comprehensive language; giving psychological support all the time.

Evidence appraisal

Validity of the results: This study was not a systematic review; thus, the appraisal criteria mentioned in Chapter II could not be applied. However, the process of literature review was used as a framework for appraisal. The reviewed studies shown in the reference list included review articles, and descriptive studies. The process of how to review the literatures was not clear. The protocol came from the literature review plus conclusions from the working group who developed this protocol. No explicit information of the content validity was addressed; thus, the validity of the review was questionable.

Nature of the results: The reviewed studies did not include RCTs; thus, the appraisal criteria (treatment effects for outcomes measured and the precision) mentioned in Chapter II could not be applied.

Applicability: Even though the review might not follow the standard process of systematic review, the nursing intervention protocol does guide nursing practice to help establish bonding between mother and Down syndrome baby. Nursing activities shown in the protocol that can be applied at Kurigram Sadar Hospital include encouraging skin-to-skin care and breastfeeding, promoting rooming-in, strengthening the mothers through emotional support, talking with the mothers about the similar family traits of the baby, and helping the baby to interact with the mother. What is currently unavailable at Kurigram Sadar Hospital is an organizational resource, or an intervention protocol for Down syndrome children in community. Thus, the nursing activities from this evidence would be much benefit for applying in my clinical setting.

Evidence IV

Title: Routine postnatal care of women and their babies.

Author/Year: National Institute for Health and Care Excellence / 2006.

Publication source: www.guidance.nice.org.uk/cg037

Summary

Background: Although the care for mothers and newborns during postnatal is not complicated, both of them must receive proper care covering all domains of needs. Health care personnel should take the evidence-based into their practice.

Objective: The guideline aimed to identify the imperative basic care that every mother and her infant baby should obtain during the first 6–8 weeks after birth, based on the best evidence available.

Methods: A guideline development group worked under the National Institute for Health and Clinical Excellence (NICE), London, UK, of which the role is to produce evidence based guidance and advice for health care practitioners. Best available evidence on postnatal care for both mother and baby were recruited and reviewed following the standard procedure of review. The guideline was also reviewed by the Guideline Review Panel, which is an independent panel that supervises the development of the guideline and takes responsibility for inspecting adherence to NICE guideline development processes.

Results: The guideline covers guidance of planning the content and delivery of care, maternal health, infant feeding, and maintaining infant health. The following recommendations were selected to present as they were relevant to the psychological support for the mother and the establishment of mother-infant bonding:

1. At each postnatal contact the healthcare professional should:

1) asking the mother about her health and well-being and that of her baby. Any symptoms reported by the mother or identified through clinical observations should be assessed;

2) offering precise and consistent information with clear explanations to empower the mother to take care of her own health and that of her baby;

3) encouraging the mother and her family to share any concerns in relation to their physical, social, mental or emotional health, and discussing the issues with them;

4) documenting any specific problems in the nursing care plan and following-up.

2. Parenting and emotional attachment

1) assessing for emotional attachment at each postnatal contact;

2) home-visiting to promote mother-infant emotional attachment;

3) encouraging the mother to develop social networks as this, in turn, will promote positive mother-infant interaction;

5) advising and encouraging the mother to attend group based parent-training programs design to promote emotional attachment between mother and infant;

6) offering fathers information and support for adjusting to their new role and responsibilities.

Evidence appraisal

Validity of the results: As this evidence was an evidence-based guideline, the methodological quality assessment of each included studies was followed the standard procedure outlined by the NICE. Usually, new evidence is checked 2 and 4 years after publication; and if needed, all or part of the guideline will be updated. Thus, the validity of the guideline should be guaranteed.

Nature of the results: The effects/outcomes of practice based on the guideline were not reported. However, according to the NICE, whenever the guideline is used in any organizations, the NICE Implementation External Reference Group is formed of three panels to determine the cost impact, clinically audit, and support front-line professionals to implement NICE guideline.

Applicability: The guideline advises the essential practice to mothers and their normal infant at postnatal period. Some guidance in particular to what help reduce concerns in mothers and promote emotional attachment between mothers and infants can be applied to cases of mothers and Down syndrome babies too. The advices are practical if applied at Kurigram Sadar Hospital; however, some skills needed to be trained for health personnel. For example, nurses' communication skill must be sufficient when sharing information, encouraging the mothers and families to share their concerns, empowering the mothers and families to take role of care, and home-visiting to promote the bonding.

Evidence V

Title: Early contact versus separation: Effects on mother–infant interaction one year later

Author: Bystrova, K., Ivanova,V., Edhborg, M., Matthiesen, A., Ransjo-Arvidson, A., Mukhamedrakhimov, R., Uvnas-Moberg, K., and Widstrom, A., (2009).

Publication source: Birth, 2009, 36(2), 97-109.

Summary

Background: Today, skin-to-skin care, breastfeeding on baby's demand, and rooming-in have become common practices in many maternity wards of many countries. However, a tradition of separation of the mother and her baby after birth and sometimes combining with hard swaddling of the baby still exists in some parts of Russia. The role of separation versus closeness after birth on maternal interaction at one year was explored in this study.

Objective: The objective of this study was to compare long-term effects on mother-infant interaction at one year of four practices used in the delivery and maternity wards, including Group 1: placed infant skin-to-skin after birth plus rooming-in, Group 2: placed infant in the mother's arms after birth plus rooming-in, Group 3 kept infant in the nursery since birth, and Group 4 kept infant in the nursery after birth but roomed-in in the maternity ward.

Methods: One hundred and twenty four mother-infant dyads participated in this longitudinal study. A two-factor design was used; that is, the first factor was baby's location and the second factor was apparel (swaddle or not swaddled). The two factors combined resulted in a total of eight treatment combination. Healthy infants were randomly assigned to four main study groups based on the location of the first two hours of life: Group 1, skin-to-skin group, n = 33; Group 2, mother's arms group, n = 33; Group 3, nursery group, n= 30; and Group 4, reunion group, n = 28. At one year after birth, observation scores of the mother-infant interaction through videotape using the Parent-Child Early Relational Assessment (PCERA) were obtained.

Results: The infants receiving skin-to-skin contact showed significantly better self-regulation and less emotional negativity and irritability than the infants in the other groups, at one year after birth. Moreover, infants in Group I & II who were

allowed to early breast feed showed more positive PCERA than those in separated groups. The infants who were separated from their mothers during the first two hours of life, with or without reunion after that, had suboptimal PCERA pattern than the other groups. In addition, compared to their counterparts, mothers of swaddled infants showed significantly less responsiveness to the infant, less positive affective involvement with the infant, and less mutual and reciprocal interaction in the dyads.

Evidence appraisal

Validity of the results: This study employed randomized control trial with single blind design. The process of random assignment was concealed using opaque sealed envelopes containing the assignment to the study groups. The background characteristics of the subjects in each group were presented without being statistical compared; however, the comparison was made between the dropouts and the remains. The videotape assessors were blinded to group assignment.

Nature of the results: The effects of 'skin-to-skin contact' and 'swaddling' on mother-infant interaction at one year after birth were statistically significant. The findings were consistent with previous studies resulting in the confirmation of its precision.

Applicability: The subjects in this study were similar to the target group of my care; that is, the mothers and their infants during the early hours of life. Even though the outcomes in this study were not exactly the mother-infant bonding, the interaction between them at one year after birth resulted from the good bonding. Thus, the study results confirm that skin-to-skin contact plus rooming-in during the first 2 hours after birth is the good practice to promote mother-infant interaction lasting for a long term. Also, early breastfeeding evidently supports the interaction. The findings are worth applying in the care of my patients.

3.2 Conclusion of the evidences reviewed

The evidences identify the early support from nurses to help establish bonding between a mother and normal healthy newborn as follows:

1. Very early skin-to-skin care (or a naked Down syndrome infant with or without cap is placed prone on the mother's bare chest about 30-40 minutes post birth) and early breastfeeding should be performed to promote bonding.

2. In case that early skin-to-skin care is not practical, early breastfeeding should be used to compensate the lack of close contact.

3. Subsequent breastfeeding and skin-to-skin care should also be promoted and encouraged so that the process of bonding formation can continue. A time table to record breastfeeding and skin-to-skin care received should be developed to ensure the consistency of such intervention given.

4. Swaddling a baby should be avoided because it limits the baby's movements and also impede the body language.

5. Rooming-in should be facilitated to promote close contact and opportunity to get to know each other between the mother and the baby.

In addition, there is also another evidence indicating that most parents were satisfied with the disclosure of the diagnosis of Down syndrome within 24 hours; the mother' psychological stages of acceptance of the baby with Down syndrome should be assessed; and the emotional and information support should be given accordingly.

3.3 Recommendations for Practice

Upon the completion of review of the five relevant papers with various levels of evidence, the recommendations for helping establish bonding between mothers and their newborns with Down syndrome at Kurigram Sadar Hospital, Bangladesh are as follows:

1. The disclosure of the diagnosis of Down syndrome should be informed within 24 hours. Even though the first information of the diagnosis is performed by doctors, nurses should be able to provide subsequent information in terms of basic knowledge of Down syndrome. The amount of information, timing, and the frequency should be taken into consideration by concerning the context of crisis and need of the mother and family.

2. The mother should be assessed for her psychological stages of acceptance of the baby with Down syndrome (that is, impact stage, denial stage, sadness and pain stage, adaptation stage, and reorganization stage) so that relative responses and proper support from nurses will be given. For example, during a denial stage, the mother still has a positive expectation towards the baby and reject the reality. Nurses should not bombard her with much information. Psychological support and time is essential during this stage.

3. After being informed of the diagnosis of Down syndrome, the mother is usually left in shock and grief. The only healthcare personnel who spend most of the time with the mother and family are nurses. Despite of no authority to inform the diagnosis, the provision of psychological nursing care to the mother and information support is absolutely authorized and within the scope of practice.

4. Very early skin-to-skin care (or a naked Down syndrome infant with or without cap is placed prone on the mother's bare chest about 30 minutes post birth) and early breastfeeding should be performed to promote bonding. These two activities should be performed no later than the first 2 hours of life. During this period, the mother is not informed the diagnosis yet; and it is possible that the Down syndrome is not recognized by health care personnel in a delivery room as well. No matter the diagnosis is known or not, initiation of skin-to-skin care and breastfeeding at the very beginning is helpful for subsequent bonding establishment.

5. In case of being unable to provide early skin-to-skin care, early breastfeeding should be practiced to compensate the lack of close contact.

6. Subsequent breastfeeding and skin-to-skin care should be promoted and encouraged. Oxytocin release stimulated by mother-infant touch and close contact during skin-to-skin care and breastfeeding creates feelings of love and relieves stress and pain which, in turn, facilitate the bonding. In this light, time table to record breastfeeding and skin-to-skin care received should be developed to ensure the consistency of such intervention.

7. Swaddling a baby should be avoided because it limits the baby's movements and also impede the body language. To establish bonding, a mutual and joyful interaction is important. Swaddling causes difficulty for the Down syndrome baby to respond with his synchronic body movements when the mother talks to.

8. Rooming-in should be practiced as this strategy opens wide range of opportunity to close contact and learn the baby' s features and cues, resulting in falling in love with and accepting the baby.

CHAPTER IV
CONCLUSION AND SUGGESTIONS

4.1 Conclusion

Mother-infant bonding is a unique and long-term emotional tie that has a significant influence on the well-beings of mother and infant. The birth of Down syndrome baby can affect the establishment of bonding. Usually, the mother is in the stages of shock and denial. If nurses do not proper intervene during this stage, it may be too late for the dyad of mother and Down syndrome baby to form such affective tie. The author, as a Bangladeshi nurse working at Kurigram Sadar Hospital in Bangladesh, have concerned about this issue due to none of nursing intervention to provide early support to help the mothers establish the bonding with their Down syndrome newborn babies. Thus, this study was conducted to summarized current evidence about nursing interventions and significant concerns for promoting bonding between mothers and their newborn with Down syndrome.

After searching related articles from the selected databases with the addressed key, none of systematic review, guideline, and RCT specific to the aim of the study were found. As a result, relevant evidences mostly targeting at mother and normal child were recruited. Finally, 5 review articles and research papers with various levels of evidence were recruited. Significant findings were retrieved to guide recommendations for nursing practice with the target group.

One current evidence indicates that most parents were satisfied with the disclosure of the diagnosis of Down syndrome within 24 hours; and the mother should be assessed for her psychological stages of acceptance of the baby with Down syndrome and given proper support accordingly.

The other evidences identify the early support from nurses to help establish bonding in a dyad of mother and normal healthy infant as follows:

1. Very early skin-to-skin care (or a naked Down syndrome infant with or without cap is placed prone on the mother's bare chest about 30-40 minutes post birth) and early breastfeeding should be performed to promote bonding.

2. In case that early skin-to-skin care is not practical, early breastfeeding should be used to compensate the lack of close contact.

3. Subsequent breastfeeding and skin-to-skin care should also be promoted and encouraged so that the process of bonding formation can continue. A time table to record breastfeeding and skin-to-skin care received should be developed to ensure the consistency of such intervention given.

4. Swaddling a baby should be avoided because it limits the baby's movements and also impede the body language.

5. Rooming-in should be facilitated to promote close contact and opportunity to get to know each other between the mother and the baby.

The significant findings from the reviewed evidences were adjusted for use to promote bonding between mothers and their newborns with Down syndrome. The recommendations for practice including proper timing to inform the diagnosis, psychological support relevant to the stage of acceptance of the baby with Down syndrome, early and subsequent skin-to-skin care and breastfeeding, discouragement of swaddling, facilitation of rooming-in are proposed.

4.2 Suggestions

4.2.1 Implications for practice:

The recommendations for practice derived from this study are merely preliminary and need more work in terms of evidences and process of guideline development to achieve the goal. The provision of early support for mothers to establish bonding with their Down syndrome babies, in fact, cannot be given separately. To achieve the optimal child outcomes, help must be given holistically and integrated with other program/intervention activities, like disclosure of the diagnosis of the baby's diagnosis, emotional support relevant to the mothers' psychological stages of acceptance of the babies, and information support relevant to the child's

condition and help needed. Thus, if possible, the key healthcare personnel and administrative team at Kurigram Sadar Hospital have to put these issues on a table so that the process of help for Down syndrome baby and family can be integrated and holistic from the beginning of prenatal period.

Certain in-service and short course training programs should be designed for Bangladeshi nurses at Kurigram Sadar Hospital to improve their competency needed for providing support to the mothers and families of Down syndrome children. For example, nurses should be equipped with communication skill so that they can form warm relationship with the clients and provide information support more effectively. As well, with proper counselling technique, nurses can provide psychological support more confidently and in a timely manner. Additional trainings for such competency as communication and counselling skills are essential. At least, one nurse from each maternity ward should be promoted for the trainings.

4.2.2 Implications for research:

A pilot study should be conducted to explore the feasibility of the recommendations for practice derived from the current study. A quasi-experimental or experimental research design may be employed to illustrate maternal and child outcomes as well as satisfaction from both mothers and healthcare personnel when very early skin-to-skin care, early and subsequent breastfeeding, and rooming-in are introduced into nursing practice with mothers and Down syndrome babies. The study findings will, in turn, be used as evidence to support the further guideline.

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