



Related visual impairment to mother-infant interaction and development in infants with bilateral retinoblastoma



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ABSTRACT

Purpose: This study was conducted with infants diagnosed with bilateral retinoblastoma (RB) and their mothers. It explored characteristics of the mother-infant interaction, the infants' developmental characteristics and related risk factors.

Method: Cross-sectional statistical analysis was performed with 18 dyads of one-year-old infants with bilateral RB and their mothers.

Results: Using the Japanese Nursing Child Assessment Teaching Scale (JNCATS) results showed that infants with RB had significantly lower scores compared to normative Japanese scores on all of the infants' subscales and "Child's contingency" ($p < 0.01$). Five infants with visual impairment at high risk of developmental problems had a pass rate of 0% on six JNCATS items. There were positive correlations between Developmental quotients (DQ) and JNCATS score of "Responsiveness to caregiver" ($\rho = 0.50$, $p < 0.05$) and DQ and "Child's contingency" ($\rho = 0.47$, $p < 0.05$).

Conclusions: Infants with visual impairment were characterized by high likelihood of developmental delays and problematic behaviors; they tended not to turn their face or eyes toward their mothers, smile in response to their mothers' talking to them or the latter's changing body language or facial expressions, or react in a contingent manner in their interactions. These infant behaviors noted by their mothers shared similarities with developmental characteristics of children with visual impairments. These findings indicated a need to provide support promoting mother-infant interactions consistent with the developmental characteristics of RB infants with visual impairment.

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1. Introduction

Retinoblastoma (RB) is an intraocular malignancy in infants occurring on the retina. The annual diagnosis in Japan is 80 infants; 100% of bilateral RB cases are hereditary. The mean age of diagnosis for the malignancy is 7.5 months for bilateral RB and

tumors can be directly visualized. Current eye-preservation therapy for RB consists of chemo-reduction therapy combining focal therapies in early infancy. In Japan, the cure rate of intraocular tumors has increased to above 90% (Suzuki, 2008; The committee for the national registry of retinoblastoma, 1992). The aim of treatment has changed to improving children's quality of life by preserving the eyes and visual function. RB infants experience repeated examinations to directly monitor the tumor prognosis and focal therapy under anesthesia. There are many concerns about visual impairment, and second cancer, long-term developmental effects are a concern (Bornstein et al., 2012; Yanagisawa, 2009; Wilson et al., 2006).

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Mothers of bilateral RB infants feel conflicting emotions about this life-threatening illness and eye loss and care in their RB infants; their complicated concerns include developmental effects on school learning and heredity (Dodge-Palomba, 2008; Watkinson and Graham, 2005; Brady, 2003). On the other hand, mothers of infants with illness build special characteristics in the mother-child relationship to relieve their infants' pain; the mothers experience mental burdens coping with the responsibility of maintaining cooperation and feeling exhausted (van Dijk et al., 2007; Young et al., 2002). The importance of support by specialists to improve the exhausted mothers and children's relationships and to maintain this cooperation was noted (Fraiberg, 2014; Nagayoshi et al., 2011; Askin, 2000; Klaus and Kennell, 1985; Tamar et al., 1990; Sumner and Spiez, 1994). The Barnard Model theorizes that social and emotional development is promoted through mother-infant interactions from early infancy. The theory defined that both mother and infant have to fulfill their responsibilities to ensure a smooth interaction; however, illness and developmental problems interfere with infants' intended roles and may cause parenting stress for their mothers (Sumner and Spiez, 1994). Previous studies on infants with bilateral RB and visual impairment showed developmental delay and problematic behaviors from one to two years old. These infants could not sufficiently and contingently respond to their mothers; that caused interference with mother-infant interactions (Nagayoshi et al., 2015, 2011). Furthermore, mothers of RB infants in treatment periods sensed the appearance of specific behaviors potentially seen in infants with pervasive developmental disorders (Nagayoshi et al., 2016). These studies suggested that there was some interference between RB infants and their mothers that prevented a successful mother-infant interaction. To determine the risk factors for such interference, further studies controlling factors were required because of the small number of subjects.

The mothers of RB infants recognize changes in infants' behaviors because of visual impairment; infants showed delays in cognitive development (Bornstein et al., 2012; Sheppard et al., 2005; Ek et al., 2002). Educational and developmental special support for visually impaired infants was suggested (Dodge-Palomba, 2008; van Dijk et al., 2007; Watkinson and Graham, 2005; Brady, 2003). It has been reported that treatments for other pediatric cancers and developmental delays correlate with neurocognitive impairment and radiotherapy. Studies showed a late effect mostly in children who received cranial radiotherapy (CRT) for brain tumors. Especially those children who had pituitary and hypothalamic tumors were at risk of neuroendocrine deficiencies. Specifically, these deficiencies for working memory, attention, executive functioning, processing speed and memory contributed to decline in intellectual ability and IQ (Turner et al., 2009; Askins and Moore, 2008; Krull et al., 2008; Schatz et al., 2000). Children with cancer including acute lymphoblastic leukemia (ALL) who received RT demonstrated lower IQ scores. In particular, the group receiving both RT and intra-thecal (IT) chemotherapy represented weakened visual-motor integration, fine-motor skills, nonverbal memory, and arithmetic skills (Dowell et al., 1991). Though research should focus on infants with visual impairment requiring early support for growth in object recognition (Fraiberg, 2014; Yamamoto, 2006; Igarashi, 2005), only a few studies to determine the risk factors for RB infant developmental characteristics have been conducted (Nagayoshi and Hirose, 2015a, 2015b).

The objectives of this study were based on the Barnard Model, to clarify: A) characteristics of bilateral RB infants' behaviors through mother-infant interactions; B) factors related to developmental characteristics on parenting stress; and C) consistent nursing care practices.

2. Methods

2.1. Study design and participants

A hospital-based study was performed at a specialized hospital in Japan. Participants included mother-infant dyads with infants between the ages of 12- and 24-months with bilateral RB and who agreed to participate in the study (Nagayoshi et al., 2015; Nagayoshi et al., 2016).

2.2. Instruments

2.2.1. Visual acuity

The diagnosis for visual impairment was validated using functional vision that included tumor size, tumor area, and condition of the ocular fundus and retina. We defined total visual acuity of both eyes below 0.1 as visual impairment based on World Health Organization criteria.

2.2.2. Mother-infant interaction

The Japanese version of the Nursing Child Assessment Teaching Scale (JNCATS) was used to assess the quality of mother-infant interaction. JNCATS is based on the Barnard Model and scientific behavioral observation (Sumner and Spiez, 1994). The Japanese version (Hirose and Teramoto, 2010) has high correlation and reliability (Cronbach's $\alpha = 0.76$) with the original version (Cronbach's $\alpha = 0.87$). Scores are given by observing reactions of the infants (aged 0–36 months) and their mothers during play with a novel toy. The scales consist of 73 items and six subscales, including four for the mother and two for the infant. The scale includes 32 items to assess the contingency aspect in interactions. Smooth mother-infant interaction results in higher scores. To observe characteristics of behavior differences between RB and healthy infants, the pass rate (percent rated as “yes”) of each JNCATS items was calculated and compared to the normative data (Hirose and Teramoto, 2010).

2.2.3. Infant development

Developmental assessment of infants was administered using the Hiro D-K Developmental Diagnosis Scale (HD-KDDS). HD-KDDS was used for analytical evaluation of infants with visual impairment aged two months to five years in Japan (Nakagawa and Kanaya, 1992). Developmental age of three areas in motor development, two areas in intellectual development, and five areas in social development were compared to their chronological age. Developmental quotients (DQ) were calculated using conversion tables and compared with their chronological ages.

2.2.4. Infant behavior

The Infant Behavior Checklist-R (IBC-R) was used for evaluating specific behavior due to the influence of visual impairment. IBC-R was used for screening pervasive developmental disorder and the effects of early intervention in infants below two years of age. Their reliability (Cronbach's $\alpha = 0.81$) and validity have been verified (Kanai et al., 2004). The cutoff score was six. All 24 items were evaluated on a two-point scale and higher scores indicated more problematic behavior.

2.2.5. Maternal parenting stress

The Japanese version of the Parenting Stress Index (PSI) was used to assess the mother's parenting stress. The PSI identifies parents who have difficulty providing care for children with developmental risks of mental and behavioral problems. The Japanese version of the PSI's correlation and reliability (Cronbach's $\alpha = 0.94$) to the original version (Cronbach's $\alpha = 0.95$) has been

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