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Factors related to home health-care transition in trisomy 13

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Trisomy 13 (T13) is accompanied by severe complications, and it can be challenging to achieve long-term survival without aggressive treatment. However, recently, some patients with T13 have been receiving home care. We conducted this study to investigate factors related to home health-care transition for patients with T13.We studied 28 patients with T13 born between January 2000 and December 2014. We retrospectively compared nine home care transition patients (the home care group) and 19 patients that died during hospitalization (the discharge at death group). The median gestational age of the patients was 36.6 weeks, with a median birth weight of 2,047 g. Currently, three patients (11%) have survived, and 25 (89%) have died. The home care group exhibited a significantly longer gestational age (38.9 vs. 36.3 weeks, $p = 0.039$) and significantly larger occipitofrontal circumference Z score (−0.04 vs. −0.09, $p = 0.019$). Congenital heart defects (CHD) was more frequent in the discharge at death group, with six patients in the home care group and 18 patients in the discharge at death group (67% vs. 95%, $p = 0.047$), respectively. Survival time was significantly longer in the home care group than in the discharge at death group (171 vs. 19 days, $p = 0.012$). This study has shown that gestational age, occipitofrontal circumference Z score at birth, and the presence of CHD are helpful prognostic factors for determining treatment strategy in patients with T13.

KEYWORDS
congenital heart defects, gestational age, home care, occipitofrontal circumference, trisomy 13

1 | INTRODUCTION

Trisomy 13 (T13) is a chromosomal condition associated with severe intellectual disability and physical abnormalities that affects approximately 1 in 10,000 births (Carey, 2010). T13 presents with various clinical symptoms and signs including impaired growth, severe developmental delay, characteristic craniofacial features such as microcephaly, coloboma of the eye, low-set ears, cleft lip and palate, central apnea, upper airway obstruction, congenital heart defects (CHD), urological complications, umbilical hernia, orthopedic complications, and cutaneous symptoms (capillary hemangioma of the frontal region of the head and aplasia cutis congenita of the

parietal and occipital regions) (Baty, Jorde, Blackburn, Carey, 1994; Bruns, 2011).

As fatal complications are often observed in T13 patients, long-term survival is not expected without aggressive treatment. However, a few authors have reported cases of patients with T13 surviving as long as 4–11 years (Baty, Blackburn, et al., 1994; Bruns, 2011). Specifically, case reports of long-term survival with home health care included a 6-year-old child, who exhibited the behavior of searching for something to grab onto when attempting to stand, and an 11-year-old child who was able to respond to social play by mimicking simple gestures and walk with support (Hsu and Hou, 2007). These reports demonstrated that patients with T13 might undergo development to a certain level. Among long-term survivors with T13, atrial septal defects (ASD) and ventricular septal defects (VSD) occur in approximately 60%, feeding-related disorders in approximately 80%, respiratory-related problems in approximately 60%, and renal or urological issues in approximately 30% of patients. Therefore, occasionally, intensive medical care is necessary even after transition to home health care (Hsu and Hou, 2007).

The treatment strategies for T13 differ between institutions. This may be attributed to varying complications and unclear long-term prognosis in infants with T13. Furthermore, treatment requires tremendous medical resources and poses a major burden to the patient's family. Therefore, the present study aimed to investigate the factors related to home health-care transition in order to provide useful information to medical personnel and families involved in the management of children with T13.

2 | PATIENTS AND METHODS

The cohort included 28 children diagnosed with T13 and born between January 1, 2000 and December 31, 2014 at the following seven hospitals: Nagoya University Hospital, Japanese Red Cross Nagoya Daiichi Hospital, Tosei General Hospital, Anjo Kosei Hospital, Okazaki City Hospital, Ogaki Municipal Hospital, and Central Hospital, Aichi Human Service Center. Participants were divided into groups according to their respective outcomes as follows: 9 patients that transitioned to home health care (the home care group) and 19 patients that died during hospitalization (the discharge at death group). These patients were then compared in terms of maternal factors, perinatal factors, and neonatal factors. These factors, which were studied retrospectively from medical records, included maternal age, pregnancy and delivery history, infertility treatment, prenatal chromosomal analysis with amniocentesis, sex, gestational age, birth weight (BW), height and occipitofrontal circumference (OFC) at birth, small for gestational age (SGA), Apgar score, resuscitation at birth, CHD, severe congestive heart failure (defined as heart failure judged by each attending physician to be related to death), severe pulmonary hypertension (defined as cases received nitric oxide inhalation therapy or judged by each attending physician to be related to the cause of death), cardiac surgery, diseases requiring surgical intervention except for cardiac surgery, central nervous system malformation, chromosomal analysis, survival time, cause of death, and home health-care status. The standard body measurement differs according to gestational age, so we conducted a statistical analysis by using the *Z* score. Gestational age was calculated from the date of last menstruation or from ultrasonographic findings in early pregnancy; SGA was defined as those patients with birth weight less than two standard deviations (SD) relative to the gestational age. We also investigated the therapeutic approaches of each attending physician for children with T13, especially for CHD, and whether they took a proactive or a passive approach in providing treatment or refrained from administering treatment. We defined the proactive approach as intensive care, where the patient received the standard treatment for patients without chromosomal abnormalities, and the passive approach as palliative care, where the patient did not receive cardiac surgery, tracheal intubation, respiratory management, or any cardiopulmonary resuscitations.

For statistical analysis, the Wilcoxon test and Fisher exact test were used for comparisons, with the level of significance set at $p < 0.05$. Continuous variables are presented as median values with interquartile ranges (IQR). Survival rates were compared between the home care and discharge at death groups using the Kaplan–Meier method (log rank).

The present study was conducted with approval from the ethics committee of Nagoya University Hospital (approval code 2014-0364).

3 | RESULTS

3.1 | Overall characteristics

The median maternal age was 32 years (range, 29–36 years), with 10 mothers being primiparous (36%). Three pregnancies (11%) were the result of infertility treatment (two cases by in vitro fertilization-embryo transfer and one case by intracytoplasmic sperm injection). One woman (4%) received a prenatal diagnosis using chromosomal analysis with amniocentesis. The study included 12 male infants (43%) and 16 female infants (57%), with a median (IQR) gestational age of 36.6 weeks (range, 34.7–38.7 weeks). Median birth weight, median height at birth, and median OFC at birth were 2,047 g (1,718–2,502 g), 45.0 cm (40.8–46.4 cm), and 30.0 cm (28.6–31.5 cm), respectively. Seven patients (25%) were SGA. Median Apgar scores at 1 and 5 min were 5 (2–7) and 6 (4–9), respectively. Congenital heart defects was observed in 24 patients (86%), which included 6 patients with patent ductus arteriosus (PDA) (21%), 10 with ASD (36%), 10 with VSD (36%), 5 with tetralogy of Fallot (18%), 3 with double outlet right ventricle (11%), and 3 with pulmonary atresia (11%). Central nervous system malformations were observed in seven patients (25%), with three patients having cerebellar hypoplasia (11%), two patients with holoprosencephaly (7%), two patients with agenesis of the corpus callosum (7%), and one patient with lissencephaly (4%). Umbilical hernia was observed in eight patients (29%) and anal atresia was observed in two (7%). The median length of the first admission was 35 days (range, 11–103.5 days). Twenty-five patients (89%) died with

the median survival time as 31 days (range, 9.5–136.5 days). The cause of death was respiratory related in nine patients (32%), including respiratory failure in seven (25%) and pneumonia in two (7%); cardiovascular related in nine (32%), including heart failure in eight (29%); pulmonary hypertension in four (14%); and infection in three (11%), including Enterobacter infection, rotavirus enteritis (4%), and peritonitis (4%), respectively; unknown cause in one (4%); and sudden cardiorespiratory arrest in three (11%).

3.2 | Comparison of clinical factors between the two groups

Maternal age, percentage of primiparous mothers, percentage of infertility treatment, and percentage of chromosomal analysis with amniocentesis were not different when comparing maternal factors of the home care and discharge at death groups (Table 1).

With respect to neonatal factors, gestational age ($p = 0.039$), BW ($p = 0.015$), and OFC at birth ($p = 0.017$) were significantly greater in the home care group (Tables 2 and 3). Investigation using *Z* score for each gestational age showed that the *Z* score of BW was not significantly different between the two groups ($p = 0.389$), whereas the *Z* score of OFC at birth was significantly larger in the home care group ($p = 0.019$) (Table 3).

Regarding karyotype, all nine patients in the home care group had full trisomy. Seventeen patients were had full trisomy (89%) including one patient with translocation (5%), and one patient being mosaic (5%) in the discharge at death group; no significant difference was observed between the groups ($p = 0.451$).

Regarding CHD, the home care group had a significantly lower percentage compared to the discharge at death group ($p = 0.047$), and severe congestive heart failure were also significantly lower in home care group ($p = 0.021$). In regard to severe pulmonary hypertension, there were no significant difference between the two groups. The percentage of central nervous malformations and diseases requiring surgical intervention except for cardiac surgery were not significantly different between the groups (Table 4).

Regarding the therapeutic strategies used by each attending physician, the proactive approach as intensive care was performed in seven patients (78%); and the passive approach, as the palliative care in two patients (22%) in the home care group. On the other hand, in the discharge at death group, intensive care was performed for 14 patients (74%) and palliative care for 5 (26%). No significant difference was found between the two groups ($p = 0.82$). In the comparison among the therapeutic strategies, three patients (33%) in the home care group and 11 (58%) in the discharge at death group were intubated. Tracheostomy was performed once in both the home care group (11%) and discharge at death group (5%). These strategies related to respiratory management did not show any significant difference. Four patients (44%) in the home care group but none in the discharge at death group underwent palliative surgery for CHD ($p = 0.002$; Table 5).

The median survival time was significantly longer in the home group than in the discharge at death group (171 days [115–1,455 days] vs. 19 days [3–42 days]; $p = 0.012$) (Figure 1). The cause of death was less frequently cardiovascular related in the home care group than in the discharge at death group ($p = 0.035$; Table 6). A more detailed examination revealed that four of the six patients in the home care group received palliative pulmonary artery banding, and no cardiovascular-related death occurred. Meanwhile, in the discharge at death group, eight patients had severe heart failure (89%) and seven had severe pulmonary hypertension (78%).

TABLE 1 Maternal factors

	Home care group ($n = 9$)	Discharge at death group ($n = 19$)	*p*
Maternal age (years) (IQR)	31 (28–34)	32 (29–36)	0.661
Primiparous/multiparous (percentage of primiparous)	3/6 (33)	7/12 (58)	0.777
Infertility treatment (yes/no) (percentage of yes)	0/9 (0)	3/16 (16)	0.207
Chromosomal analysis with amniocentesis (yes/no) (percentage of yes)	0/9 (0)	1/18 (5)	0.483

IQR, interquartile range.

4 | DISCUSSION

In summary, we experienced the following results in this study: gestational age was greater in the home care group than in the discharge at death group, OFC at birth and the *Z* score of OFC at birth were significantly larger in the home care group and the home care group had a significantly smaller proportion of patients with CHD.

The natural sequence of individuals with T13 is reportedly such that 28% die in the week following birth, 44% in the month after birth,

TABLE 2 Neonatal factors

	Home care group ($n = 9$)	Discharge at death group ($n = 19$)	*p*
Gestational age (weeks) (IQR)	38.9 (36.7–39.5)	36.3 (33.9–37.6)	0.039
Male/female (percentage of males)	4/5 (44)	8/11 (42)	0.907
SGA/non-SGA (percentage of SGA)	0/9 (0)	6/13 (32)	0.214
Apgar score (1 min) (IQR)	6 (5–7)	3 (1–6)	0.203
Apgar score (5 min) (IQR)	8 (7–9)	5 (4–6)	0.326

IQR, interquartile range; SGA, small for gestational age.

TABLE 3 Anthropometry at birth

	Home care group ($n = 9$)	Discharge at death group ($n = 19$)	p
Birth weight at birth (g) (IQR)	2,596 (2,047 to 2,760)	1,960 (1,574 to 2,296)	0.015
Z score of birth weight at birth (IQR)	−0.12 (−0.14 to −0.08)	−0.11 (−0.22 to −0.06)	0.389
Height at birth (cm) (IQR)	46.5 (42.2 to 49.8)	44.0 (40.0 to 45.5)	0.055
Z score of height at birth (IQR)	−0.03 (−0.06 to 0.02)	−0.04 (−0.12 to −0.02)	0.150
OFC at birth (cm) (IQR)	31.5 (29.7 to 33.8)	29.3 (28.0 to 30.6)	0.017
Z score of OFC at birth (IQR)	−0.04 (−0.06 to 0.01)	−0.09 (−0.11 to −0.04)	0.019

IQR, interquartile range; OFC, occipitofrontal circumference.

and 88% in the year after birth (Irving, Richmond, Wren, Longster, & Embleton, 2011). However, some authors have reported infants with T13 showing long-term survival up to 4–11 years of age (Baty, Jorde, et al., 1994; Bruns, 2011; Kaneko et al., 2008). Moreover, 59% of patients with T13 went home health care after birth (Janvier et al., 2016). In our cohort, 8 of 28 patients (29%) were able to transition to home health care. Three of our patients (11%) are currently alive and living at home. Some infants with T13 receiving home health care might expect a more long-term survival.

The relationship between OFC at birth and prognosis has been reported in previous articles (Nelson, Hexem, & Feudtner, 2012; Petry et al., 2013). The results in our study have also shown that OFC at birth and Z score of OFC at birth were significantly larger in the home care group. In our study, there was no significant difference in the incidence of central nervous malformations; we could not explain the reason for this, but OFC might be a prognostic indicator in patients with T13.

In this study, the proportion of those with CHD in the home care group was significantly smaller than those in the discharge at death group. Therefore, the presence of CHD has a significant impact on prognosis. Owing to the small number of patients who received palliative surgery in this study, we could not conclude anything about palliative surgery. However, considering that the four patients who underwent a palliative surgery were transferred to home health care, whereas none of the patients in the discharge at death group underwent a palliative surgery ($p = 0.002$) in this study, palliative pulmonary artery banding might increase the chance of patients with T13 to be transferred to home health care. Recently, various cases of cardiac surgery for patients with T13 have been reported. Kaneko et al. (2008) showed that medications and surgical intervention for PDA improved the outcome in T13. A retrospective American study showed that cardiac surgery was performed in 14.6% of patients with T13 in Ontario between 1991 and 2013 (Nelson, Rosella, Mahant, & Guttmann, 2016). Currently, more patients with T13 receive cardiac surgery (Carey, 2005, 2010; Josephsen, Armbrecht, Braddock, & Cibulskis, 2016). Maeda et al. (2011) showed that half of the patients with T13 had CHD with PH, and 25% of the patients received cardiac surgery. In half of the patients who received surgery, PH improved after the surgery. This report also suggested that cardiac surgery could be considered in patients with T13 who had no severe extracardiac problem because technical difficulties in surgical treatment of simple CHD had already been overcome (Maeda et al., 2011). According to the findings in this study, the discharge at death group had significantly higher prevalence of congenital heart disease, and none of them underwent cardiac surgery. In addition, significantly more cardiovascular-related deaths

TABLE 4 Complications

	Home care group ($n = 9$)	Discharge at death group ($n = 19$)	p
Congenital heart disease (yes/no) (percentage of yes)	6/3[a] (67)	18/1[b] (95)	0.047
Severe congestive heart failure (yes/no) (percentage of yes)	0/9 (0)	8/11 (42)	0.021
Severe pulmonary hypertension (yes/no) (percentage of yes)	1/8 (13)	7/12 (37)	0.159
Central nervous malformation (yes/no) (percentage of yes)	1/8[c] (11)	6/13[d] (46)	0.158
Diseases requiring surgical intervention except for cardiac surgery (yes/no) (percentage of yes)	2/7[e] (22)	7/12[f] (37)	0.439

VSD, ventricular septal defect; ASD, atrial septal defect; PDA, patent ductus arteriosus; TOF, tetralogy of Fallot; DORV, double outlet right ventricular.
[a]Three cases of VSD, two cases of ASD, and one case of PDA.
[b]Seven cases of VSD, eight cases of ASD, five cases of PDA, five cases of TOF, two cases of DORV, and three cases of pulmonary atresia.
[c]One case of ependymal cyst.
[d]One case of holoprosencephaly, one case of cerebellar hypoplasia, one case complicated by both cerebellar hypoplasia and agenesis of the corpus callosum, two cases of agenesis of corpus callosum, and one case of lissencephaly.
[e]Two cases of umbilical hernia.
[f]Five cases of umbilical hernia, one case of anal atresia, one case complicated by both umbilical hernia and anal atresia.

TABLE 5 Comparison among the therapeutic strategies

	Home care group (n = 9) (%)	Discharge at death group (n = 19) (%)	p
Intubation	3 (33)	11 (58)	0.22
Tracheostomy	1 (11)	1 (5)	0.57
Positive pressure assist ventilation	3 (33)	3 (16)	0.41
Cardiac surgery	4 (44)	0 (0)	0.002

TABLE 6 Cause of death

	Home care group (n = 6)[a] (%)	Discharge at death group (n = 19) (%)	p
Respiration related	3 (33)	6 (32)	0.413
Cardiovascular related	0 (0)	9 (47)[b]	0.035
Infection	0 (0)	2 (11)	0.407
Etiology unknown	3 (33)	1 (5)	0.035

[a]Number of deaths (three survivors).
[b]Nine patients with complex heart defects, eight patients with congestive heart failure, and seven patients with pulmonary hypertension.

occurred among the patients. Thus, radical operation may confer a high-risk and heavy burden for patients with severe extra cardiac problem. However, palliative surgery such as pulmonary artery banding is less burdensome and provides a greater possibility that patients can be transferred to home health care. To clarify this, further research focused on palliative surgery is necessary.

Our policy for terminal patients is to arrange an environment where the patients can spend less time on treatment and more time with their families. In this study, one patient was discharged at the family's request. The patient survived only a short time at home, but this might be preferable to spending the final hours at the hospital. Most parents fear pain, medical complexity, and life in hospitals, and do not want to subject their children to burdensome interventions and pain in hospitals (Janvier et al., 2016). For patients who are expected to survive for only a short period, medical interventions that prolong life at the expense of family time should be avoided and an environment for terminal patients to share their precious remaining time with their families whether at home or at the hospital should be arranged. A guideline for determining a plan of care for newborns with severe diseases proposed that all newborns have the right to receive appropriate medical care based on their best interest (Tamura, 2004). An optimal treatment should be selected on the basis of a common understanding between the physician and the family, which depends on the individual case (Andrews et al., 2016).

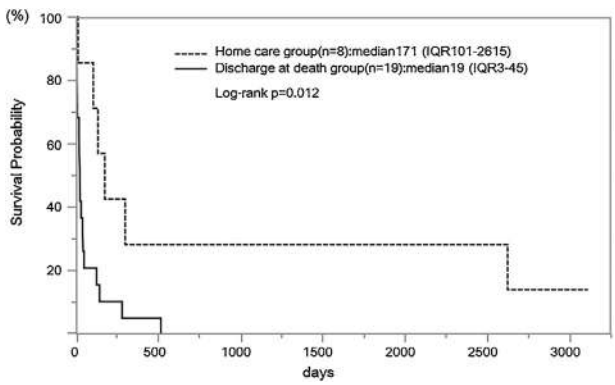

FIGURE 1 Survival curves of patients with trisomy 13. Kaplan–Meier survival curve of the home care group (red) and discharge at death group (blue). Survival time is significantly shorter in the discharge at death group than in the home care group (p = 0.012)

This study had a few limitations. First, it was based on a multicenter retrospective review. Even though the criteria for home health care were based on stabilized respiratory and nutritional management following surgeries for CHD and/or any surgical issues, the treatment strategies and/or a transition to home care were not completely unified. The physical conditions of most of the patients in the home care group were relatively stable. In contrast, some patients in the discharge at death group died immediately after birth. This might contribute to bias in the statistical analysis. In addition, we were unable to perform a multivariate analysis because of the small sample size. A study design with more patients is desired for these reasons.

Recently, use of non-invasive prenatal genetic testing (NIPT) has become widespread. Even though some patients with T13 undergo continued development throughout their lives (Zoll, Wolf, Lensing-Hebben, Pruggmayer, & Thorpe, 1993), there has been a concern that termination of T13 fetuses may become common place. Some patients with T13 survive long term; therefore, it is important to provide accurate information to the family and to decide the optimal treatment strategies, which takes into consideration individual features of each infant with T13. As the treatment strategy for a newborn with T13 should be decided after considering each individual case, we recommend referring to GA, OFC at birth, Z score in OFC at birth, and the presence of CHD, all of which are important prognostic factors.

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