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**ORIGINAL RESEARCH:
EMPIRICAL RESEARCH - QUANTITATIVE**

Parental uncertainty about transferring their adolescent with congenital heart disease to adult care

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Abstract

Aims: To study parent's levels of uncertainty related to the transfer from pediatric to adult care in adolescents with congenital heart disease (CHD) and to identify potentially correlating factors.

Background: Parents acknowledge that during transition they struggle with finding ways of feeling secure in handing over the responsibility and letting go of control. Well-prepared and informed parents who feel secure are most likely better skilled to support their adolescent and to hand over the responsibility.

Design: A cross-sectional study.

Methods: Overall, 351 parents were included (35% response rate). Parental uncertainty was assessed using a Linear Analogue Scale (0–100). Data were collected between January - August 2016. Potential correlates were assessed using the readiness for transition questionnaire and sociodemographic data.

Results: The mean parental uncertainty score was 42.5. Twenty-four percent of the parents had a very low level of uncertainty (score 0–10) and 7% had a very high level (score 91–100). Overall, 26% of the mothers and 36% of the fathers indicated that they had not started thinking of the transfer yet. The level of uncertainty was negatively associated with the level of perceived overall readiness. Adolescents' age, sex, CHD complexity, and parental age were not related to uncertainty.

Conclusion: A wide range in the levels of uncertainty was found. Parents who were less involved in the care, or perceived their adolescent as readier for the transition, felt less uncertain. Still, thirty percent of the parents had not started to think about the transfer to adult care.

KEYWORDS

adolescents, congenital heart disease, nursing, parental uncertainty, readiness for transition, transfer, transition

1 | INTRODUCTION

To be a parent to a child with a chronic condition is linked to a plethora of challenges during both childhood and adolescence (Coffey, 2006). In addition to the desire to be a good parent and to give their child the best life possible, these parents are confronted with additional challenges due to their child's condition. Some also struggle to carry the burden of caring for their sick child and the family (Jackson, Higgins, Frydenberg, Liang, & Murphy, 2018). When the child reaches adolescence, parents meet new demands when starting to shift roles regarding handing over the responsibility for healthcare management to their adolescent (Burström, Öjmyr-Joelsson, Bratt, Lundell, & Nisell, 2016)

1.1 | Background

Depending on the country and healthcare setting, at the age of 15–18 years most adolescents will transfer their medical follow up from paediatric care to adult care (Hilderson et al., 2009). When approaching the actual time for transfer to adult care, it has been reported that both parents and adolescents often feel insecure and uncertain about the transition process and the transfer of care (Bratt, Burström, Hanseus, Rydberg, & Berghammer, 2018; van Staa, van der Stege, Jedeloo, Moll, & Hilberink, 2011). The families may experience anxiety in leaving the paediatric specialist and often lack information about the new caregiver (Rutishauser, Akre, & Suris, 2011) and their role in the preparation for transfer (Clarizia et al., 2009) and this can be a significant barrier to a successful transfer of responsibilities. Questions about whether the adolescent is ready to take over the responsibility for their health and care often emerge (van Staa et al., 2011). Other concerns that has been reported are thoughts about the new caregiver and whether they are competent enough and if they will take good care of their adolescent (Burström et al., 2016).

It has been reported that parental support is crucial during the transition period and that well prepared and informed parents feel secure and most likely are better skilled to support and to hand over responsibility to the adolescent (Heath, Farre, & Shaw, 2017; Sable et al., 2011; Silversides et al., 2010).

The concept of parental uncertainty related to illness is well established (Mishel, 1983). Uncertainty arises when a situation is ambiguous and unpredictable or if there is a lack of clarity from the caregiver. According to this concept, parental illness uncertainty questionnaires have been developed. A recent meta-analysis on parental illness uncertainty showed that illness uncertainty may have an impact on the psychological functioning and distress in parents to children with paediatric chronic illnesses (anxiety, depression, and psychological distress) (Szulczewski, Mullins, Bidwell, Eddington, & Pai, 2017). Further, it has been acknowledged that parental illness uncertainty is associated with caregiver demands and child depression symptoms. Because of these findings, it is suggested that healthcare providers (HCP) need to provide the parents with medical information to improve the understanding and communication with the healthcare management (Chaney et al., 2016). How parents cope

Why is this research needed?

- Parents are a crucial support during the transition to adulthood for adolescents with chronic disease. It is important to investigate the level of uncertainty in parents since this can have implications for the adolescents during this vulnerable period.
- Feelings of uncertainty in leaving the paediatric specialist and the lack of information about the transfer to a new healthcare setting can be a significant barrier to a successful transfer.
- Identifying and exploring uncertainty in parents may have implications for nursing interventions such as providing support to parents in handing over the responsibility to the adolescent.

What are the key findings?

- There was a wide variation in the perceived parental uncertainty.
- Higher levels of perceived transition readiness were associated with lower levels of parental uncertainty.
- Thirty percent of the parents had not thought about the upcoming transfer for their adolescent.

How should the findings be used to influence policy/practice/research/education?

- The parental uncertainty scale has the potential to be used in clinical settings to guide nursing interventions. However, further research is needed to evaluate the uncertainty scale in clinical settings
- There is a need to add parental uncertainty during transition to the research agenda since it can be a barrier for the parents in handing over the responsibility to the adolescent, which is an important part of the transition process.
- There is a need for improvement in the preparation of both the adolescents and their parents during the transition prior to transfer to adult care. Nurses have a key role in preparing and supporting both stakeholders.

and manage the situation has an impact on the level of illness uncertainty. (Szulczewski et al., 2017).

Although uncertainty related to the illness has been studied before, less is known about the level of parental uncertainty related to the transfer to adult healthcare. To optimize parental support during the transition and transfer to adult care and to be able to intervene if necessary, it is pertinent to study parental uncertainty and potential correlating factors that are affecting the uncertainty.

In the present study, a group of parents of adolescents with congenital heart disease (CHD) was selected because CHD represents a

typical example of a chronic childhood condition. It is the most common congenital malformation with a birth prevalence of up to 9.3 cases/1,000 newborns (van der Linde et al., 2011) and in many cases it requires lifelong medical follow-up (Goossens, Bovijn, Gewillig, Budts, & Moons, 2016).

2 | THE STUDY

2.1 | Aims

The aims of the study were (a) to study parents' levels of uncertainty related to the transfer from paediatric to adult care in adolescents with CHD; and (b) to identify any factors that might correlate with parents' level of uncertainty.

2.2 | Design

A cross-sectional study was performed in four university hospitals. The study was part of a national transition project on adolescents with CHD (Swedish Transition Effects Project Supporting Teenagers with chrONic mEdical conditionS, STEPSTONES-CHD).

2.3 | Participants

The Swedish registry of CHD (Swedcon) was used to identify eligible patients. Parents were included in the study if they had a child fulfilling the following criteria: age 14–18 years, born with CHD and being under active follow-up at one of the four participating university hospitals. Parents were excluded if their child had any syndromes affecting cognitive abilities, had undergone heart transplantation, or had a non-structural heart disease or if the parents were illiterate or did not speak Swedish. A total of 1,186 eligible parents of 593 adolescents fulfilled the inclusion criteria.

2.4 | Data collection

The questionnaires were sent along with information about the study and a consent form to all eligible parents. Sociodemographic information was collected through a background questionnaire (see Table 1). The complexity of the adolescent's disease was retrieved from the medical records and classified as mild, moderate, or complex according to the guidelines from Task Force 1 of the 32nd Bethesda conference (Warnes et al., 2001). To increase the number of responders, a modified Dillman approach was used (Dillman, 1983). Specifically, two reminders were sent by mail after 3 and 5 weeks and with a last reminder by phone call after 7 weeks.

2.4.1 | Primary outcome – Parental uncertainty

Uncertainty-scale

The Uncertainty-Scale is a linear analogue scale assessing parental uncertainty regarding the upcoming transfer to adult care for adolescents with CHD. The uncertainty scale was developed for this study since no

TABLE 1 Adolescents' and parents' characteristics

Participants	Adolescents, N = 194	Mothers, N = 189	Fathers, N = 162
Sex, n (%)			
Female	87 (45)		
Age (years)	15.7 (1.1)	46.9 (5.3)	49.3 (5.5)
Complexity of the CHD, n (%)			
Mild	58 (30)	n.a.	n.a.
Moderate	83 (43)	n.a.	n.a.
Complex	53 (27)	n.a.	n.a.
Education, n (%)			
Elementary school	105 (56)	13 (8)	14 (10)
Junior high school	80 (43)	57 (33)	60 (41)
University	0	95 (56)	69 (47)
Other	2 (1)	6 (3)	3 (2)
Vocational status, n (%)			
Employed	n.a.	149 (81)	122 (77)
Self-employed	n.a.	16 (9)	26 (17)
Unemployed	n.a.	8 (4)	4 (2)
Student	n.a.	3 (2)	0
On sick leave	n.a.	6 (3)	5 (3)
Other	n.a.	2 (1)	2 (1)
Civil status, n (%)			
Married	n.a.	140 (74)	132 (82)
Living together with a partner	n.a.	20 (10)	18 (11)
Living alone	n.a.	23 (12)	8 (5)
Other	n.a.	5 (3)	2 (1)
Living with my child's parent, n (%)			
Yes	n.a.	151 (80)	138 (86)

n.a., not applicable.

suitable questionnaire was found for assessing parental uncertainty regarding the shift from paediatric to adult care. The parents were asked to indicate their perceived level of uncertainty for their adolescent's coming transfer to adult CHD care on a vertical linear analogue scale, ranging from 0 (not uncertain at all) to 100 (extremely uncertain). For parents who had not thought about the transfer, an extra alternative was given.

2.4.2 | Correlates

Sociodemographic information included the adolescents' sex, age, and education level and the parents' sex, age, educational level, vocational status, marital status, and cohabitation status. Clinical information pertained to the complexity of the heart defect.

Overall transition readiness, adolescents' responsibility, and parental involvement were assessed using the readiness for transition questionnaire (RTQ) parental version (Gilleland, Amaral, Mee, & Blount, 2012). The questionnaire contains items about adolescents' responsibility (9 items), parental involvement (9 items) and the perceived overall transition readiness (2 items), all measured on a four-point Likert scale

(not at all responsible/involved; somewhat responsible/involved; mostly responsible/involved; completely responsible/involved), and the added option “not applicable.” A total mean score for the parental assessment of adolescent’s responsibility and parental involvement was calculated if there were not more than four items missing per individual in each domain (a half-scale approach) (range 1–4). The additional option “not applicable” for each item is counted as a missing value. The overall readiness score was calculated as the mean of the two adolescent transition readiness items, with a higher score indicating a higher level of adolescent readiness. This questionnaire has a parental version to be filled out by the parents, which is used for this study.

Aggregated scores for parental uncertainty, overall readiness, adolescents’ responsibility, parental involvement, and parental age were obtained by averaging the separate scores for the mother and the father. If only one parent was available, the score of that parent was used as the overall parental uncertainty score.

2.5 | Validity, reliability, and rigour

The Uncertainty scale was developed for this study. Face validity was performed by testing the instrument on four parents who participated in the testing on three different occasions. The tests led to some revisions, including changing the scale to 0–100 because 0–10 was considered too narrow and changing the wording from “parents” to “you as a parent.” In addition, many parents had never reflected on the future transfer and thus could not answer the question about how much uncertainty they felt. Therefore, another option was added, and they could mark the answer “I have not thought about the transfer.” After these changes, the instrument was considered suitable to be tested for measuring the level of uncertainty in parents to adolescents with CHD.

The RTQ was translated by into Swedish following a standardized translation procedure using forward and backward translation in a two-stage procedure by the research team (Wild et al., 2005). Four Swedish-speaking researchers with knowledge in the field performed the forward translation independently. Discrepancies were resolved between their versions. A backward translation into English was then performed by an authorized translator and native speaker of English and further discrepancies were resolved (Wild et al., 2005).

An additional response option (not relevant) was added after evaluating face validity to the items related to adolescents’ responsibility and parental involvement. This option was included since there were items related to medication and frequent contacts with HCP, which is less relevant for patients with CHD. Moreover, the item related to healthcare insurance was removed since Swedish healthcare covers persons independently of their age. Internal consistency was confirmed in adolescents with kidney transplants, with Cronbach $\alpha > 0.7$ (Gilleland et al., 2012).

2.6 | Data analysis

All data were analysed using IBM SPSS Statistics for Windows version 24 (IBM Corp., Armonk, NY, USA). Descriptive statistics were

expressed in absolute numbers and percentages for nominal variables and in terms of means and *SDs* for continuous variables. The Wilcoxon signed-rank test was used for between-group comparisons in paired groups. Unpaired two-group analyses for nominal data were performed using chi-square tests. Cohen’s *d* was calculated to assess the effect size of significant values (Cohen, 1988). To analyse the agreement in perceived uncertainty between parents of the same adolescent (dyads), an intra class correlation (ICC) (two-way random, absolute agreement) was calculated. The strength of agreement was determined using the following cut-offs: poor agreement is < 0.40 ; fair to moderate agreement is $0.40–0.59$; good agreement $0.60–0.74$; excellent agreement $0.75–1.00$ (McDowell, 2006). To appraise the magnitude of the effect sizes, we used the cut-off values for Cohen’s *d*: small effect size = $0.2–0.5$; medium effect size = $0.5–0.8$ and large effect size = > 0.8 (Cohen, 1988). To explore potential correlates of the perceived level of uncertainty, univariate linear regression analyses were performed. The assumptions of linearity of residuals and the independence of observations were met by assessing Durbin–Watson statistics and normal probability plots. The level of significance was set at $p < 0.05$ and two-sided tests were applied.

2.7 | Ethical considerations

Ethics approval for the study was received from the institutional review board in Gothenburg (Dnr 953-13) and the study was performed according to the Helsinki Declaration (World Medical Association, 2013).

3 | RESULTS

In all, 351 parents (189 mothers and 162 fathers) were included in the study (35% response rate). The mean age of the mothers was 46.9 (*SD* 5.3) years and the mean age of the fathers was 49.3 (*SD* 5.5) years. Most the parents were employed (77%–81%) or self-employed (9%–17%). The mean age of the adolescents was 15.7 (*SD* 1.1) years and 45% were girls. The distribution of the CHD complexity was relatively similar among the three categories of mild, moderate, and complex conditions (Table 1).

The mean parental uncertainty score was 42.5 (*SD* 30.1, $n = 144$). The distribution of scores showed that 24% of the parents had a very low level of uncertainty (score 0–10) and 7% had a very high level (score 91–100) (Figure 1). Overall, 26% of the mothers and 36% of the fathers indicated that they had not started thinking of the transfer yet. To investigate to what extent mothers and fathers to the same child are in line with each other in their level of uncertainty, an ICC analysis was performed between 157 matched parents. The ICC was 0.737 (95% confidence interval 0.58–0.84, $p = 0.005$) demonstrating a good agreement between both parents. Yet, mothers (46.1, *SD* 32.4) generally had a significantly higher uncertainty level than fathers (41.2, *SD* 33.3) ($Z = -2.136$, $p = 0.03$). This difference, however, was not clinically meaningful given the low Cohen’s *d* of 0.15.

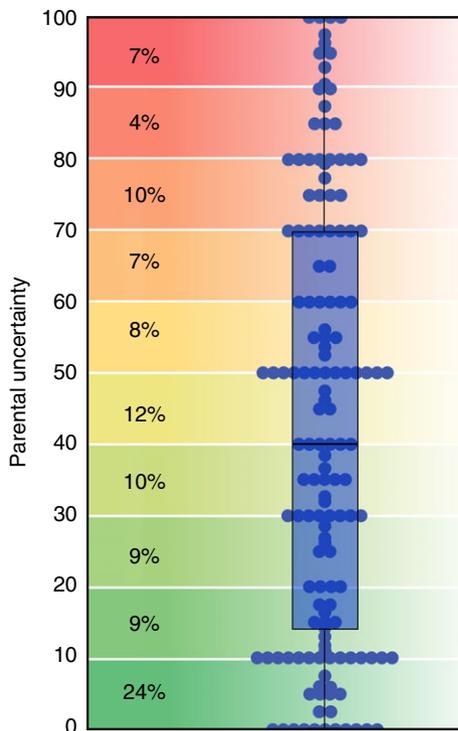


FIGURE 1 The distribution of the Parental Uncertainty scores ($n = 144$ parents)

The univariate regression analysis indicated that increased levels of perceived overall readiness ($\beta = -0.6$, $p = 0.005$) and a lower level of parental involvement ($\beta = 0.35$, $p = 0.005$) were associated with a lower level of uncertainty. Adolescent age, sex, CHD complexity, adolescents' responsibility, and parental age were not associated with the level of uncertainty (Table 2).

The proportion of parents (mothers $n = 49$, fathers $n = 58$) reporting "I have not thought about the transfer" did not differ between being a parent of a boy or a girl (mothers' $p = 0.47$, fathers' $p = 0.49$), nor did the complexity of the disease display any significant differences for mothers ($p = 0.84$), although it did for fathers ($p = 0.037$). With increasing age of the adolescent, parents reported a decrease in "I have not thought about the transfer" ($p = 0.001$) (Table 3).

4 | DISCUSSION

In the present study, we assessed perceived uncertainty in relation to the transfer to adult care of parents of adolescents with CHD. In addition, factors potentially associated with the level of uncertainty were explored.

This study showed a wide range in levels of uncertainty. Some parents did not feel uncertain at all, whereas some parents were extremely uncertain. These differences could not be explained by sociodemographic or clinical characteristics. The only significant correlates with the level of uncertainty were the parental assessment of

TABLE 2 Univariate linear regression analysis of parental perceived uncertainty

Correlates	Univariate analysis		
	B (SE)	β	p-value
Adolescents' sex	-3.2 (5.0)	-0.05	0.5
Adolescents' age	0.6 (2.4)	0.2	0.8
CHD complexity			
Mild	9.0 (6.6)	0.14	0.2
Moderate	8.7 (6.1)	0.15	0.2
Complex	-	-	-
Parental age	0.3 (0.5)	0.5	0.5
Overall transition readiness	-18.4 (2.3)	-0.6	0.005
Adolescents responsibility	4.8 (3.5)	0.1	0.2
Parental involvement	11.5 (2.6)	0.35	0.005

TABLE 3 Relationship of adolescents' characteristics of mothers and fathers who had not thought about the transfer

	"I have not thought about the transfer"			
	Mother, N = 49		Father, N = 58	
	N (%)	p-value	N (%)	p-value
Adolescents'				
Female	20 (25.3)	0.47 [†]	25 (35.7)	0.49 [†]
Male	29 (30.2)		33 (41.3)	
CHD complexity				
Mild	14 (25.5)	0.84 [†]	23 (53.5)	0.037 [†]
Moderate	20 (28.2)		25 (36.2)	
Complex	15 (30.6)		10 (26.3)	
Adolescents' age				
14 years	18 (56.3)	0.001 [†]	22 (78.6)	0.001 [†]
15 years	15 (35.7)		18 (48.6)	
16 years	10 (22.7)		8 (26.7)	
17 years	6 (10.5)		10 (18.2)	

[†]Chi-squared test.

the adolescent's overall readiness for transition and the parental involvement. It is understandable that parents who perceive their adolescents as being more ready for taking over responsibility for their care and for being transferred to adult care do feel less uncertain (Heath et al., 2017). The result also showed that a high level of parental involvement might be an indication of an uncertain parent. This may be an argument for assessing parental uncertainty during the transition, because at that period, there ought to be a shift in the healthcare responsibilities from the parents to the adolescents.

We also observed that the older the child was, the more the parents had started to think about the transfer of care. Indeed, as the adolescent gets closer to the age of transfer, this becomes a more relevant subject for the parents. It is important to raise this issue early on and not at the time when the young person faces the actual transfer to adult care. It might be difficult for parents to know how

to support their adolescents in an appropriate way (Bratt et al., 2018; Burström et al., 2016) and discussing this subject with the parents can help them understand their upcoming role and the shift in responsibilities associated with this stage. Furthermore, discussing the transfer of care with the parents is a way of helping the young persons because the parents have a strong influence on how this process is experienced by the young person (Heath et al., 2017; Sable et al., 2011; Silversides et al., 2010). Experiences of uncertainty in parents can inhibit adolescents' development towards healthcare autonomy (Sable et al., 2011) and it has been argued that increased levels of uncertainty and perceived parental stress can lead to negative consequences such as difficulties in promoting the independence of the adolescent or a lack of perceived trust in the adolescent to assume responsibility for their own care (Santacroce, 2003; Stewart & Mishel, 2000).

Thirty percent of the parents of the adolescents in the present study reported that they had not yet started to think about the transfer. This might be of concern knowing that the actual transfer to adult care in Sweden occurs at the age of 18 years. Most probably this reflects that parents and their adolescents might not have been informed about the imminent transfer from paediatrics to adult care and such information ought to be provided during the transition phase. Indeed, international guidelines stipulate that the transfer to adult care should be preceded by a transition process where the adolescent and their family are prepared for the shift in roles and for the transfer of care (Rosen, Blum, Britto, Sawyer, & Siegel, 2003; Sable et al., 2011). When information is given to the parents about the transfer, this might prevent them from feeling uncertain (Kirk, 2008). In turn, this might assist parents in providing support to their adolescent in developing more autonomy during the transition period (Beacham & Deatrck, 2013).

Mothers and fathers, in general, experienced a rather similar level of uncertainty. When dyads were directly compared, a good agreement in the levels of uncertainty was found. The most obvious explanation of this good agreement is that most parents were living together, thus providing the possibility to share concerns and to support each other when needed.

It might be counterintuitive that there was no difference in the level of uncertainty with respect to the complexity of the disease. It might be expected that parents of children with complex heart defects would have more concerns and therefore feel more uncertain; however, because such patients and their families have more frequent medical follow-ups (Landzberg et al., 2001), they might be better informed about the coming transfer and have more possibilities to discuss this transfer with the HCP. A somewhat surprising finding was the difference in uncertainty regarding disease complexity for mothers and fathers. There was no significant difference in uncertainty regarding disease complexity for mothers, but there was a significant difference for the fathers. The results may indicate that the fathers of children with mild conditions are starting to think about the transfer later than mothers do. It may be because the child is not affected by the condition in day-to-day life. However, more complex CHD was associated with more fathers who thought about the transfer.

During the transition, the main focus for the HCP is to prepare the adolescents for the transfer. However, nurses must not forget the parents (Bratt et al., 2018), since parental concerns about the transition may be an obstacle for the adolescent to take up responsibility for health (Clarizia et al., 2009). Given that some parents were extremely uncertain and the fact that the level of uncertainty could not be predicted by other variables tested here, there is a need to include an assessment of parental uncertainty during the transitional care for adolescents with CHD. If a high level of uncertainty is observed, nurses and healthcare professional can attempt to determine the reasons for such uncertainty and to see if supportive interventions might be implemented. This study contributes with new knowledge about factors associated with parental uncertainty regarding the transfer to adult care.

4.1 | Limitations

There are methodological considerations that need to be discussed. First, the uncertainty scale was developed specifically for this study and has not been used in other prior studies. Therefore, our results are not comparable with the findings of other studies. Second, the instrument is a one-item self-assessment scale, and this makes it difficult to discern the reason for the uncertainty perceived by the parents. However, the face validity for the scale showed that the parents perceived the scale as easy to understand and to use. Further psychometric testing would be appropriate. Third, a national register for CHDs Swedcon was used to identify eligible subjects for the study. Despite the use of a modified Dillman approach, the response rate was relatively low, which hampers the generalizability of the findings. Due to the fact that no information about the non-responders was available, we could not perform a non-responder analysis. Fourth, due to the nature of a cross-sectional study, no directionality of associations could be made. It would be interesting to see if uncertainty has an impact on the perception of transition readiness or vice versa and longitudinal studies are needed to explore this issue.

5 | CONCLUSION

A wide range in levels of uncertainty was observed. Mothers and fathers had a good agreement in their perceived level of uncertainty. The level of uncertainty was not associated with the adolescent's age, gender, or disease complexity. Parents who perceived their adolescent as more ready for the transition, felt less uncertain with the upcoming transfer. The result also showed that a high level of parental involvement might indicate a high level of uncertainty. Still, thirty percent of the parents had not started to think about the transfer to adult care. These results suggest that it might be important for HCP to start up an early discussion with parents on their new, upcoming role when their child is transitioning. This is especially important because parents play a key role in supporting their child during the transition to adulthood and during the transfer to adult care.

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CONFLICTS OF INTEREST

No conflict of interest has been declared by the authors.

AUTHOR CONTRIBUTIONS

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE, <http://www.icmje.org/recommendations/>):

- Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- Drafting the article or revising it critically for important intellectual content.

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