

## RESEARCH ARTICLE

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# Transition competence as an indicator of health outcomes related to transition

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## Abstract

**Background:** Adolescents and young adults (AYAs) with chronic conditions face a transfer, defined as an actual shift from paediatric to adult-oriented health care. Transition competence as the self-perceived knowledge, skills and abilities regarding the transition process was considered extremely useful.

**Aim:** This study was designed to investigate the impact of transition competence before and after the transfer on disease-specific quality of life (QoL) and health care satisfaction of AYAs with diabetes.

**Results:** In total, a sample of  $N = 90$  AYAs with diabetes self-reported their transition competence, diabetes-specific QoL and satisfaction with care. Multiple linear regressions were used to analyse the impact of transition competence on satisfaction with care and QoL. Transition competence positively influenced the outcomes of satisfaction with care and QoL.

**Conclusion:** Young adults with diabetes showed higher transition competence scores than adolescents with diabetes.

## KEYWORDS

adolescence, chronic (health) condition, diabetes, quality of life, transition

## 1 | INTRODUCTION

Through the progress of modern medicine, survival rates of adolescents with chronic conditions are continually rising (Kennedy et al., 2007; Scheidt-Nave et al., 2008). These adolescents are facing a change from paediatric to adult-oriented health care, a process which is called *transition*. In comparison, *transfer* describes the actual shift from paediatric to adult-oriented health care, which separates the

pre-transition phase characterized by the preparation for the transfer and post-transition phase, which is marked by adjustment and learning to navigate adult care successfully (Stinson et al., 2014). The transition should be a planned, structured, well-implemented and purposeful process enabling adolescents with chronic conditions, their parents and their health care professionals to pass successfully from paediatric to adult medicine (Blum et al., 1993; Castillo & Kitsos, 2017; Huang et al., 2014; Kennedy et al., 2007).

However, the transition process is often poorly managed, negatively affecting health outcomes (Toulany et al., 2022). Negative impacts include, for example, that youth with type 1 diabetes have increased mortality rates, are more likely to be hospitalized for

**Abbreviations:** AYAs, Adolescents and young adults; DM, Chronic-specific quality of life DISABKIDS Diabetes Module; TCS, Transition competence scale; YHC-SUN, Satisfaction with care YHC-SUN short form.

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diabetes after transition, report lower QoL compared to a healthy population (Betz, 2004; Cameron et al., 2018), and showed lower patient engagement in the health care system in the future (Cameron et al., 2018; Hart et al., 2019; Yassaee et al., 2019). Commonly mentioned barriers to transition are a lack of knowledge about medication/illness or the transition process, a deficit of skills and efficacy by providers, adolescents and young adults (AYAs), or barriers emerging in the relationship of persons involved in the transition process (Gray et al., 2018). Also, the literature mentions a non-fit between the maturity level of a patient and the expectations of the health care providers. Considering the requirements set, it is little wonder that the values of diabetics are rather suboptimal (Alwadiy et al., 2021; Kapellen et al., 2018; Sandler & Garvey, 2019). For example, glycemic control was shown 2.5 higher odds to be poor in young adults in adult medicine than in adolescents in paediatric medicine (Lotstein et al., 2013). Barriers must be overcome to enable the AYAs to manage the transition as a structured and well-planned process, in particular, should include counselling on diabetes self-management, health care navigation (e.g., maintenance of supplies, scheduling of appointments), diabetes complications and differences between paediatric and adult care systems (Cameron et al., 2018; van Staa et al. 2011).

Transition readiness is important for determining the right time to transfer to adult care (Cameron et al., 2018). This construct is often used to identify the readiness and self-management ability of AYAs in transition, but measures assessing it are rarely applied in health care. The timing of transfer should be based on the individual social, personal and psychological development of adolescents with chronic conditions (Toulany et al., 2022; Yassaee et al., 2019). Thus, capturing transition readiness for transition could be a key component of a successful transition, as well as neighbouring constructs, like knowledge of the transition process (Betz & Coyne, 2020).

In addition, health care satisfaction and QoL are important aspects to consider when pre- and post-transfer states are compared with each other (Binks et al., 2007; McDonagh, 2007; Nakhla et al., 2008). Furthermore these two constructs were assessed more likely in a study with the context of transition but not within one study, thus, a further investigation of the relation of both constructs could rarely realize (Bailey et al., 2022). Cramm et al. (2013) have demonstrated that satisfaction with transitional care before and after the transfer was positively associated with emotional, physical and social domains of health-related QoL in adolescents with diabetes type 1, juvenile idiopathic arthritis and neuromuscular disorder. Therein, they ascertained that the smaller the reported discrepancy between the imagined 'best care' and the 'current care', the better the social and emotional QoL (Cramm et al., 2013). Capturing the right time for transfer is difficult, and studies cope by capturing a wide variety of constructs, but these constructs were not often related to each other in analysis (Lotstein et al., 2013; Mok et al., 2019; Virella Pérez et al., 2019), thus lacking knowledge of an underlying network of these constructs. Moreover, it is not known whether the relationships between these constructs differ in pre- and post-transition (Herrmann-Garitz et al., 2017; Menrath et al., 2018; Schmidt et al., 2016a). However, only a small percentage of the studies included in a recent

systematic review (14 of 71) focused on adult-based care (Hart et al., 2019). Studies that pay special attention to the post-transition phase are urgently needed.

## 2 | AIM

To our knowledge, health care satisfaction, disease-specific QoL and transition readiness were frequently measured as singular secondary outcomes but were not related to each other so far. Thus, important information about the interaction of the constructs that are collected in connection with transition is missing. Especially, the post-transition period lacking that information. In this study, we examine the associations between health care satisfaction, disease-specific QoL and transition readiness in pre- and post-transition period of AYAs with diabetes type 1.

## 3 | METHODS

### 3.1 | Sample

An online survey was conducted to evaluate the relationship between satisfaction with care, disease-specific QoL and transition competence. The data was collected in Germany from November to December 2016. Every participant was insured by the statutory health insurance 'Techniker Krankenkasse', which recruited the AYAs with type 1 diabetes via mail. Every eligible participant received a letter with an invitation to a fully-anonym online-survey. Informed consent procedures were completed by each participant. Eligible participants were AYAs aged 15 to 26 years and were diagnosed with type 1 diabetes according to the ICD-10 and being insured by the above-mentioned statutory health insurance. These participants were either still being treated in paediatric medicine or had completed the transfer and were treated in adult medicine. A sample of  $N = 106$  patients participated in the survey. A detailed response rate analysis could not be performed. These data were not accessible because of data security regulations and could not provide here.

### 3.2 | Study measures

The measuring of the constructs in the age ranges from 15 to 26 is difficult because most of the instruments were developed either for adolescents or adults. For all three questionnaires, the wording of the items is applicable for AYAs, because there is no wording specific for one population, like 'in your school' but the wording tends to be more informal. This is rather unusual in assessing young adults. Assessing the same questionnaire in AYAs is a well-known challenge in transition research. The chosen measurements were originally developed for adolescents but have been used in prior transition studies and performed well (Menrath et al., 2018; Schmidt et al., 2016a; Schmidt et al., 2018).

### 3.2.1 | Short form of the Youth Health Care questionnaire on satisfaction, utilization and needs (YHC-SUN-SF)

To assess health care satisfaction of children and adolescents with a chronic condition, the Youth Health Care—satisfaction, utilization and needs (YHC-SUN-SF) short-form measure was used. The short form is extracted from Module 2 of the YHC-SUN, which consists of 26 items assigned to six domains (*diagnosis/information, coordination, child-centred care, hospital environment, doctors' behaviour and school services*) (Schmidt et al., 2016b). The YHC-SUN-SF is comprised of seven items; two items regarding the subscale *diagnosis/information*, two items identifying *doctors' behaviour*, two items referring to *child-centred care* and one item reflecting general health satisfaction. A total score can be computed from the scores of the three subscales. The response choice options of the scale range from (1) 'not satisfied' to (5) 'extremely satisfied'. The scores were transformed from 6 and 30 to 0–100. A higher score corresponds with higher health care satisfaction. The internal consistency was reported with a Cronbach's alpha of 0.85. Through confirmatory factor analysis, a sufficient fit for a one-factor solution could be found; in addition, a three-factor solution (two items each) could be identified, also including one higher-order factor (Muehlan et al., 2021).

### 3.2.2 | DISABKIDS Diabetes Module

We assessed the disease-specific QoL with the disease-specific module for diabetes from the DISABKIDS Group. This instrument consists of two scales with 10 items in total and three additional items, which measure symptoms of the past year: (1) the *impact* scale, which assesses emotional reactions of needing to control diabetes every day and to maintain a strict diet. It consists of six items. (2) The *treatment* scale describes the feeling of carrying equipment and planning the treatments and is assessed using four items. The scoring on a 5-point Likert scale ranges from (1) 'never' to (5) 'always' for both scales. A higher score corresponds with a higher QoL. Cronbach's alpha values were reported with 0.84 for the *impact* scale and 0.85 for the *treatment* scale. The score was transformed to a scale ranging from 0 to 100 (European DISABKIDS Group, 2006).

### 3.2.3 | Transition competence scale (TCS)

The health-related TCS measures self-perceived knowledge, skills, abilities of self-management and competencies regarding the preparation and the progress of transition using a mean of 10 items (e.g., 'I know the difference between adult health care and child health care'). It is assessing transition readiness and also related constructs, like knowledge or self-management. The construct is quantified by a sum score ranging from 10 to 40 and can be transformed into a scale with

a range between 0 and 100. The response categories of the 4-point Likert scale ranged from (1) 'strongly disagree' to (4) 'strongly agree'. A higher score represents a higher self-perceived competence. The instrument contains three subscales: (1) *work-related preparedness*, (2) *condition-related knowledge* and (3) 'health-related competence'. A global score can also be measured, which has a reported Cronbach's alpha of 0.81 and a discrimination index ranging from 0.42–0.62 (Herrmann-Garitz et al., 2017).

### 3.2.4 | Measuring transfer

The transfer was assessed with a self-reported single item 'Did you already transferred to adult care?'. If the participants answered 'yes', we additionally asked how old they were at the time of transfer. We used this single item for grouping the participants in 'pre-transfer' and 'post-transfer'.

### 3.2.5 | Participation in previous education program

In addition to age, sex and education, we measured the participation in a previous education program. A educational program was described as workshop or case-management program to improve the transition in general or transition readiness and patient empowerment of AYAs with diabetes type 1 in particular.

## 3.3 | Data analysis

Descriptive analysis was used to display demographics and clinical characteristics (Table 1). Pearson's correlation coefficients were computed to display possible associations between the three constructs and their subscales (Table 2). To investigate the influence of transition competence and the *current state of the participants* (pre- or post-transfer) on health care satisfaction and disease-specific QoL, a multiple linear regression analysis was conducted. Additionally, gender and age were included as control variables in the analysis. Transition competence was included in the first step of the analysis, in the second step the variable 'current state of the participants' was added, and in the third step, further control variables were introduced.

## 4 | RESULTS

In total,  $N = 90$  AYAs fully completed the questionnaire and were thus included in the analysis. Their average age was  $M_{age} = 20.59$  ( $SD_{age} = 3.09$ ), and 52.2% of the participants were female.  $N = 14$  participants were currently in treatment with a paediatrician (pre-transfer;  $M_{age} = 17.42$ ,  $SD_{age} = 2.50$ ), and  $N = 76$  had finished the transfer (post-transfer;  $M_{age} = 21.25$ ,  $SD_{age} = 2.76$ ). Further demographic details are provided in Table 1.

**TABLE 1** Demographics of the groups pre-transfer, post-transfer and total.

	Pre-transfer (n = 14)	Post-transfer Group (n = 76)	Total (n = 90)
Age		(n = 75)	(n = 89)
M	17.42	21.25	20.65
SD	2.50	2.76	3.04
Range	15–25	15–26	15–26
	Count (%)	Count (%)	Count (%)
Gender			
Female	7 (50.0)	40 (52.6)	47 (52.2)
Male	7 (50.0)	36 (47.4)	43 (47.8)
Education			
<12 years	2 (14.3)	13 (17.1)	15 (16.7)
≥12 years	12 (85.7)	61 (80.3)	73 (81.1)
Others	0	2 (2.6)	2 (2.2)
Previous participation in a patient education program	(n = 14)	(n = 74)	(n = 88)
Yes	0 (0.0)	5 (6.8)	5 (5.7)
No	14 (100.0)	69 (93.2)	83 (92.2)

Scale	1	2	3	4
1. Transition competence scale (TCS total score)	1	89	85	89
2. Quality of life—impact (DISABKIDS Diabetes Module subscale ‘impact’)	0.18	1	84	88
3. Quality of life—treatment (DISABKIDS Diabetes Module subscale ‘treatment’)	0.36**	0.60**	1	86
4. Satisfaction with care (YHC-SUN-SF total score)	0.27**	0.16	0.07	1

**TABLE 2** Intercorrelations of condition-specific quality of life (DISABKIDS Diabetes M), satisfaction with care (YHC-SUN-SF) and transition competence scale (TCS).

Note: The number of participants are presented above the diagonal; DISABKIDS-Diabetes M, chronic-specific module diabetes of the DISABKIDS Group.

Abbreviations: TCS, transition competence scale; YHC-SUN-SF, Youth Health Care measure—satisfaction, utilization and needs short form.

\*\* $p < 0.01$ .

A pre-analysis of the relation of age, gender, education and previous participation in a patient education program and the interesting constructs of transition competence (TCS), disease-specific QoL (DISABKIDS Diabetes module) and satisfaction with care (YHC-SUN-SF) was conducted. The analysis revealed a significant positive correlation of gender with the DISABKIDS Diabetes module subscale ‘impact’ ( $r = 0.22$ ) and a significant positive correlation between age and transition competence ( $r = 0.29$ ). In conclusion, age and gender will be included in the regression models.

A pre-analysis of the total sample regarding data distribution of the used scales TCS and YHC-SUN-SF as well as the subscales ‘impact’ and ‘treatment’ of the DISABKIDS Diabetes module was conducted. No significant deviation parameters were found.

Further analysis of the TCS revealed that transition competence is positively related to the QoL subscale ‘treatment’ of the DISABKIDS Diabetes module ( $r = 0.60$ ). Furthermore, transition competence correlates positively with satisfaction with care as assessed with the YHC-SUN-SF total ( $r = 0.27$ ). No significant correlation was measured

between disease-specific QoL (DISABKIDS Diabetes module) and satisfaction with care (YHC-SUN-SF). Further information is provided in Table 2. Additional information on the mean and standard deviation of the scales is displayed in Table 3.

Regression analysis showed that transition competence has a significant positive influence on disease-specific QoL as measured by the subscale *impact* of the DISABKIDS Diabetes module (Table 4) but only in the second step of the analysis, after adding the variable ‘current state of the participants’ to the model. This could not be found in the third step of the regression model. The regression models for the subscale ‘treatment’ of the DISABKIDS Diabetes module and the total score of the YHC-SUN-SF are significant in all steps of the analysis (Tables 5 and 6). The variable *current state of the participants* (pre- vs. post-transfer) is not significant in all three models, but adding the variable to the models increases  $R^2$  in each of the models and highlights the impact of transition competence. The betas of all three models of this variable were negative, which indicates a negative association between the *current state of the participant* (pre- vs. post-

**TABLE 3** Sample size, mean and standard deviation of the TCS, YHC-SUN-SF and DISABKIDS Diabetes Module.

	Range	Pre-transfer			Post-transfer			Total		
		N	M	SD	N	M	SD	N	M	SD
Transition competence										
TCS total score	0–100	14	63.10	17.71	76	75.00	16.23	90	73.15	16.93
Quality of life										
DISABKIDS impact	0–100	14	63.39	12.14	75	59.01	21.05	89	59.70	19.93
DISABKIDS treatment	0–100	12	46.88	22.69	73	51.03	25.71	85	50.44	25.22
Satisfaction with care										
YHC-SUN-SF total score	0–100	14	72.32	15.30	75	68.08	20.75	89	68.75	19.97

Note: DISABKIDS-Diabetes Mod, chronic-specific module diabetes of the DISABKIDS Group.

Abbreviations: TCS, transition competence scale; YHC-SUN-SF, Youth Health Care measure—satisfaction, utilization and needs short form.

**TABLE 4** Hierarchical regression analysis summary for DISABKIDS Diabetes Module subscale *impact* (N = 86).

Step	Predictor	B	SE B	Beta	R	Δ R <sup>2</sup>
1	Transition competence scale (TCS)	0.22	0.13	0.19	0.04	0.04
2	Transition competence scale (TCS)	0.26	0.13	0.22*	0.05	0.02
	Pre- versus post-transfer	−7.32	5.93	−0.13		
3	Transition competence scale (TCS)	0.24	0.13	0.20	0.09	0.04
	Pre- versus post-transfer	−6.99	6.47	−0.13		
	Sex	7.89	4.19	0.20		
	Age	0.01	0.79	0		

\* $p < 0.05$ .

**TABLE 5** Hierarchical regression analysis summary for DISABKIDS Diabetes Module subscale *treatment* (N = 85).

Step	Predictor	B	SE B	Beta	R	Δ R <sup>2</sup>
1	Transition competence scale (TCS)	0.49	0.15	0.33**	0.11	0.11**
2	Transition competence scale (TCS)	0.50	0.16	0.35**	0.11	0
	Pre- versus post-transfer	−3.29	7.66	−0.05		
3	Transition competence scale (TCS)	0.49	0.16	0.34**	0.12	0.01
	Pre- versus post-transfer	−3.00	8.36	−0.04		
	Sex	3.78	5.26	0.08		
	Age	0.08	0.97	0.01		

\*\* $p < 0.01$ .

**TABLE 6** Hierarchical regression analysis summary for satisfaction with care (YHC-SUN-SF total score) (N = 86).

Step	Predictor	B	SE B	Beta	R	Δ R <sup>2</sup>
1	Transition competence scale (TCS)	0.33	0.13	0.27*	0.07	0.07**
2	Transition competence scale (TCS)	0.38	0.13	0.31	0.10	0.03
	Pre- versus post-transfer	−9.13	5.84	−0.17***		
3	Transition competence scale (TCS)	0.37	0.14	0.30	0.10	0
	Pre- versus post-transfer	−10.15	6.44	−0.19**		
	Sex	1.35	4.16	0.03		
	Age	0.33	0.80	0.05		

\* $p < 0.05$ , \*\* $p < 0.01$ , and \*\*\* $p < 0.001$ , coding: pre-transfer = 0, post-transfer = 1; sex: female = 1, male = 2.

transfer) and their scores of the subscales *impact* and *treatment* of the DISABKIDS Diabetes module, and the total score of the YHC-SUN-SF in contrast to transition competence, which was positively associated. The total score of transition competence was higher in the post-

transfer group than in the pre-transfer group. For the scores of the subscales *impact* and *treatment* of the DISABKIDS Diabetes module as well as the total score of the YHC-SUN-SF, the pre-transfer group showed higher scores than the post-transfer group.

## 5 | DISCUSSION

In this paper, we were able to show that transition readiness and self-perceived knowledge have a significant influence on health care satisfaction and disease-specific QoL. The *current state of the participants* concerning their position within the process of transition, either pre- or post-transfer, had no direct significant influence on the association between transition competence and health care satisfaction or disease-specific QoL. It did, however, strengthen the effect between transition readiness and the other two constructs. Transition readiness scores were higher in the post-transfer group than in the pre-transfer group, which is in line with other findings (Betz & Coyne, 2020; Yassaee et al., 2019). Higher transition competence, subjective preparedness and knowledge regarding transition were associated with higher satisfaction with care and higher disease-specific QoL.

The importance of considering patient-reported outcomes and transition readiness in a more complex context was demonstrated by Acuña Mora et al. (2022), who showed that readiness to transition had a significant positive cross-lagged effect on patient empowerment at subsequent measurement time points. This effect was not shown for quality of life, communication skills and patient-reported health. The strong, positive effect of transition readiness on patient empowerment in combination with patient activation and self-efficacy could also be found (Bal et al., 2016; Markwart et al., 2020). Also, the measurement and investigation of health care satisfaction, QoL and transition readiness were necessary to identify the special health care needs of AYAs and track their transition process and receive a more detailed overview of transition readiness. Coyne and Hallowell (2020) outline the importance to monitor different aspects of pre- and post-transfer in AYAs, like disease-specific QoL, self-management aspect or satisfaction with health care. Our study captured these three components and focused on both individuals in pre- and post-transfer. There are gaps in the coverage of standardized measurement in post-transfer (Coyne & Hallowell, 2020). Investigation of post-transition AYAs is essential; this will require standardized measurements and time intervals to evaluate successful transition services (Coyne et al., 2017). Our findings suggest that participants seem to gain a higher transition readiness in the post-transfer phase but also that the association of transition readiness was stronger associated with health care satisfaction and disease-specific QoL in AYAs with diabetes type 1 in this phase than it was in the AYAs in pre-transfer phase.

Zhong et al. (2018) investigated the health care transition readiness of AYAs in a longitudinal paediatric setting and reported results similar to our findings. The health care transition readiness increased with age, with smaller increases at older ages. Furthermore, results of another study indicated that the transition competence score was associated with psychosocial maturity and age, but the effects were weak (Moynihan et al., 2015). Measurements to assess transition readiness are considered to be an underdeveloped area (Schwartz et al., 2014), as the constructs can only be assessed with a small number of instruments (e.g., TRAQ, Transition-Q or TRxANSITION) (Schwartz et al., 2014), but there are activities directed to develop new instruments for use in health care settings (Bond et al., 2020) and standardized the assessment of transition and transfer, even for

specific chronic conditions (e.g., diabetes type 1; Al Khalifah et al., 2022). In literature, most of the studies of transition agreed that the construct readiness or maturity should be preferred over the chronological age of the AYAs to determine the start of the transfer process into adult care (Yassaee et al., 2019).

As could be shown, the transition competence of AYAs with diabetes also has a significant impact on outcomes such as health care satisfaction and disease-specific QoL. With the TCS we used in this study, two components of transition readiness as self-report were assessed, transition-specific skills and knowledge about the transition process (Yassaee et al., 2019). Studies showed that a more generic construct like health-related QoL did not reveal differences in the population reliably (Cramm et al., 2013; Menrath et al., 2018; Schmidt et al., 2018).

## 6 | LIMITATIONS

The small sample size of the pre-transfer group ( $N = 14$ ) was a strong limitation of this study. Therefore, it was not possible to analyse the associations between the groups separately, but we were able to factor in the total group effect in our analysis. A further limitation arises from the assessment via self-report measures. Thus, the potential gap between reporting a good transition competence and actual behaviour in the transition process was not addressed appropriately (Annunziato et al., 2007). Hence, results are only applicable to AYAs with diabetes. Also, the selection of instruments should be viewed with caution because the measures used were developed for the population of adolescents and not for young adults.

## 7 | CONCLUSIONS

The assessment and evaluation of transition require a comprehensive methodological approach. In our study, transition readiness, subjective preparedness and knowledge regarding transition were positively associated with satisfaction with care and disease-specific QoL. The young adults with diabetes showed higher transition competence scores than the adolescents with diabetes, which is in line with the findings of Zhong et al. (2018). The measurement of transition competence is change sensitive and thus can be used to map effects in interventions and training; it can also map these changes in young adults, providing the opportunity to map negative effects in integration in adult medicine. This forms a bridge to the current lack of tools to capture formerly adolescents with chronic conditions who are now being treated in adult medicine. In future studies, it could be investigated how maladaptive effects of young adults with chronic conditions in adult medicine could be captured and investigated.

The associations between different constructs should be looked at as well, to detect specific relations for different populations within the process of transition (pre- or post-transfer), but the analysis could not identify transition competence as a possible individual criterion for the timing of the transition. Longitudinal studies are especially suitable to discover such relations but are rarely conducted. Thus, a



systematic evaluation of processes and outcomes is often not possible due to a lack of tracking mechanisms (Gilliam et al., 2011).

## AUTHOR CONTRIBUTIONS

**Henriette Markwart:** Conceptualization; investigation; funding acquisition; writing—original draft; methodology; software. **Silke Schmidt:** Conceptualization; funding acquisition; writing—review and editing; project administration. **Ute Thyen:** Conceptualization; funding acquisition; investigation; writing—review and editing; supervision. **Gundula Ernst:** Writing—review and editing. **Holger Muehlan:** Supervision; project administration; writing—review and editing; writing—original draft; investigation; validation; methodology.

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## CONFLICT OF INTEREST STATEMENT

The authors declare that they have no competing interests.

## DATA AVAILABILITY STATEMENT

Research data are not shared.

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