

복잡 심기형을 가진 환자의 청소년기 삶

이선희¹ · 김소선²

The Life of Adolescent Patients with Complex Congenital Heart Disease

Lee, Sunhee¹ · Kim, So-Sun²

¹Instructor, College of Nursing, Eulji University, Seongnam

²Professor, College of Nursing · Researcher, The Nursing Policy Research Institute, Yonsei University, Seoul, Korea

Purpose: In the present study, an analysis of the life of adolescents with complex congenital heart disease (CHD) was done using grounded theory. Consideration was given to the socio-cultural context of Korea. **Methods:** After approval from the institutional review board of Y hospital, 12 patients ranging in age from 14 to 35 were recruited. Data were gathered using in-depth interviews. Theoretical sampling was performed until the concepts were saturated. **Results:** The results confirmed the life of adolescents with complex CHD as a 'journey to finding uniqueness of oneself as a person with CHD'. The life consisted of 3 stages. In the crisis stage, participants had a feeling of threat to self-existence, and made an effort to be the same as others. In the self-recognition stage, participants who had sufficient role-performance built self-esteem while those who did not fell into self-accusation. In the self-establishment stage, participants who reached sufficiency in independence and knowledge planned the future, whereas those who did not conformed to the realities of life. **Conclusion:** The results of present study provide help in understanding the experiences of adolescents with CHD and provide a basis for developing nursing intervention strategies for these patients.

Key words: Adolescent, Congenital heart defect, Grounded theory, Life

서론

1. 연구의 필요성

1,000 2-3
(Lee, Kim, Jung, Kim, & Choi, 2001).

5- 15%
, 85% (Lane, Lip, & Mil-
(Lee, 2001) lane, 2002).

2- 3

주요어 : 청소년, 선천성 심장병, 근거이론, 삶

*본 논문은 제1저자의 박사학위 논문의 일부를 발췌한 것임.

*This article is based on a part of the first author's doctoral thesis from Yonsei University.

Address reprint requests to : Kim, So-Sun

College of Nursing, Yonsei University, 134 Sinchon-dong, Seodaemun-gu, Seoul 120-752, Korea
Tel: 82-2-2228-3254 Fax: 82-2-392-5440 E-mail: soskim@yuhs.ac

투고일 : 2010년 2월 1일 심사회의일 : 2010년 2월 1일 게재확정일 : 2010년 6월 9일

연구 목적 및 연구 질문

(Casey, Sykes, Craig, Power, & Connor Mulholland, 1996),

(European Society of Cardiology)

2003 (Deanfield et al., 2003).

2. 연구 참여자의 선정

14 35

(Strauss & Corbin, 1998)

3. 자료 수집 방법

1) 연구 참여자에 대한 윤리적 고려

Y

2) 자료 수집 기간과 방법

2007 5 11

2. 연구 목적 및 연구 질문

1. 연구 설계

연구 방법

1 4 30 1 1 2

(Transferability)

(Dependabil-

ity)

4. 자료 분석

(Conformability)

2

Strauss Corbin (1998)

연구 결과

1. 연구 참여자의 일반적 특성

5

7

7

5

B L

(Major aorto-pulmanry collateral arteries,

MAPCAs)

C F, J MAPCAs

J

2

5. 연구의 진실성(Trustworthiness) 확보

Guba Lincoln (1981) (Credibility),

(Transferability), (Dependability),

(Conformability)

10

(Credibility)

8

2, Endocardial cush-

ion defect (ECD) 1,

1,

4,

1,

1

8

(Table 1).

Y

2. 패러다임을 이용한 범주의 분석

1984

(

Table 1. Demographic Characteristics of the Participants

Case	Gender	Age in years	Diagnosis	Age at start of treatment	No. of operations	Complication
A	M	22	TOF, PA	Newborn	3	CHF Arrhythmia
B	M	27	DORV, VSD, PS, MAPCAs	7 yr-old	5	Arrhythmia
C	M	22	TGA, PDA, VSD, Pul. HTN	21 yr-old	1	
D	F	18	PA, VSD, MAPCAs	Newborn	6	
E	M	18	PA, ASD, VSD, PDA, TR	Newborn	2	Arrhythmia
F	F	19	SV, Lt Isomerism	10 yr-old	1	
G	F	14	TOF, LPAJS	Newborn	6	
H	M	15	PS, ASD, PDA	Newborn	2	
I	F	14	TOF, PA	Newborn	5	
J	F	20	ECD	5 yr-old	2	
K	F	14	TOF, TR	Newborn	6	
L	F	35	SV, Dextrocardia, MAPCAs Rt. Isomerism, PA	8 yr-old	1	Arrhythmia. Endocarditis

TOF=Tetralogy of Fallot; PA=Pulmonary atresia; CHF=Congestive heart failure; DORV=Double outlet right ventricle; VSD=Ventricular septal defect; PS=Pulmonary stenosis; TGA=Transposition of the great arteries; PDA=Patent ductus arteriosus; Pul. HTN=Pulmonary hypertension; MAPCAs=Major aorto pulmonary collateral arteries; ASD=Atrial septal defect; TR=Tricuspid regurgitation; SV=Single ventricle; LPAJS=Left pulmonary artery junctional stenosis; ECD=Endocardial cushion defect.

Table 2. Categories and Concepts

Categories	Concepts
Perceiving oneself as being different from others	Feeling of isolation Becoming a pitiful person Being exhausted with school life Suffering between life and death
Feeling a threat to self-existence	Uncertainty Feeling of oppression from over-protectiveness Feeling of guilty
Making an effort to be the same as others	Being afraid of opening the disease Wishing to be the same as others
Feelings of a sense of belonging	Accepting themselves from sharing family members' feelings Feeling a sense of belonging from the friends' consideration Feeling a sense of belonging from the emotional support of health providers
Building self-esteem	Feeling a sense of belonging Becoming a valuable person Having self-confidence
Falling into self-accusation	Absence of trust in oneself
Managing independently	Learning ways to solve problems Self-administering heart disease treatment
Managing dependently	Depending on others in self-administering treatment Avoiding the management of heart disease
Planning for the future	Life for the people with congenital heart disease
Conforming to the realities of life	Settling for the present Living in seclusion

1984) . 1984

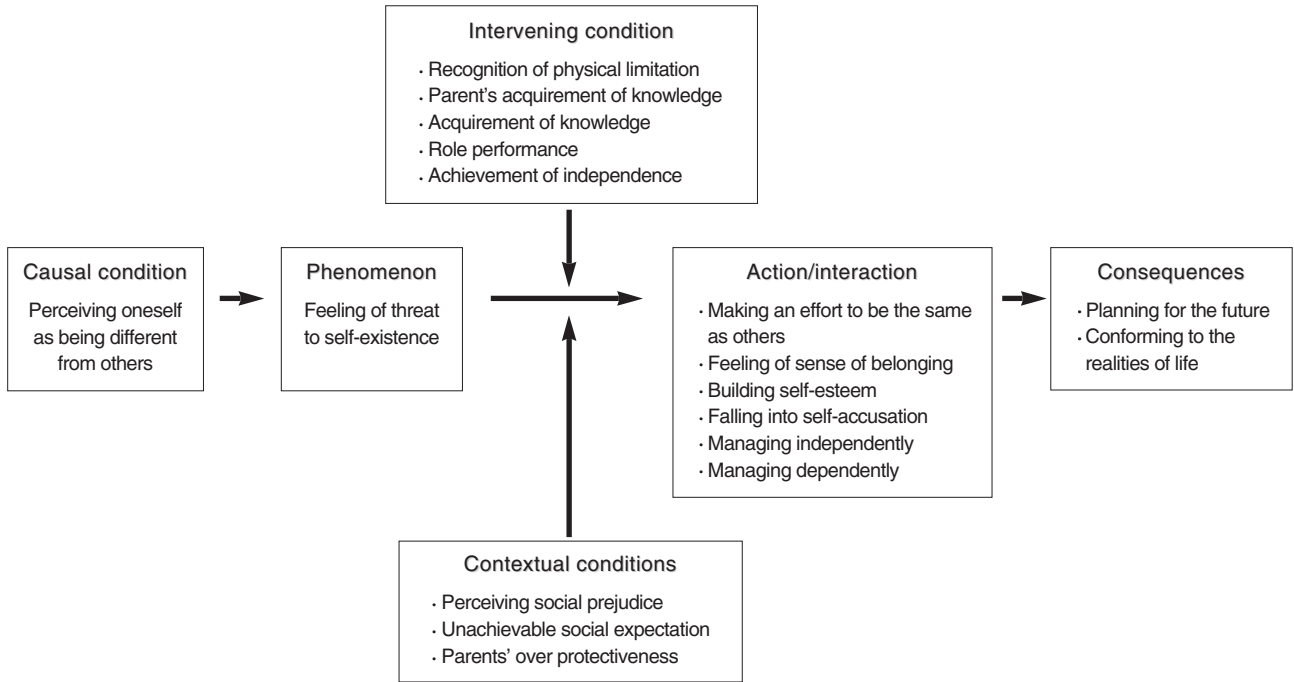


Figure 1. Paradigm of life of adolescent with complex congenital heart disease.

(Figure 1).

1) 현상

(1) 남과 다른 나를 인식함

“ 1 1 5
. 1 3 1 ..
?”

”(A)

(1) 자기존재에 대해 위기를 느낌

“ !
?
3

1980

...”(B)

2) 상황

(2) 사회적 선입견을 느낌

“

“... (L)

(3) 사회적 기대치에 미치지 못함

“... 2-3 ... (B)

“... (B)

3) 작용/상호작용

“... / ... (E)

(1) 또래와 같아지려고 노력함

“... (E)

(4) 부모의 과잉보호

“... (K)

“... (L)

(2) 소속집단으로부터 존재가치를 느낌

“... (E)

AB **

(5) 독립적으로 관리함

,

“

**

”(

....

A)

”(A)

“

“

”(F)

...(),

”(E)

(6) 의존적으로 관리함

“

”(D)

4) 결과

(3) 자기를 존중함

“

(1) 미래를 개척함

“

!

”(A)

(4) 자기를 비하함

“

...”(C)

”(D)

”(A)

(2) 현실과 타협함

1) 위기의 단계

"(B)

3. 과정 분석

?, ;

?

2) 자아인식의 단계

(Figure 2).

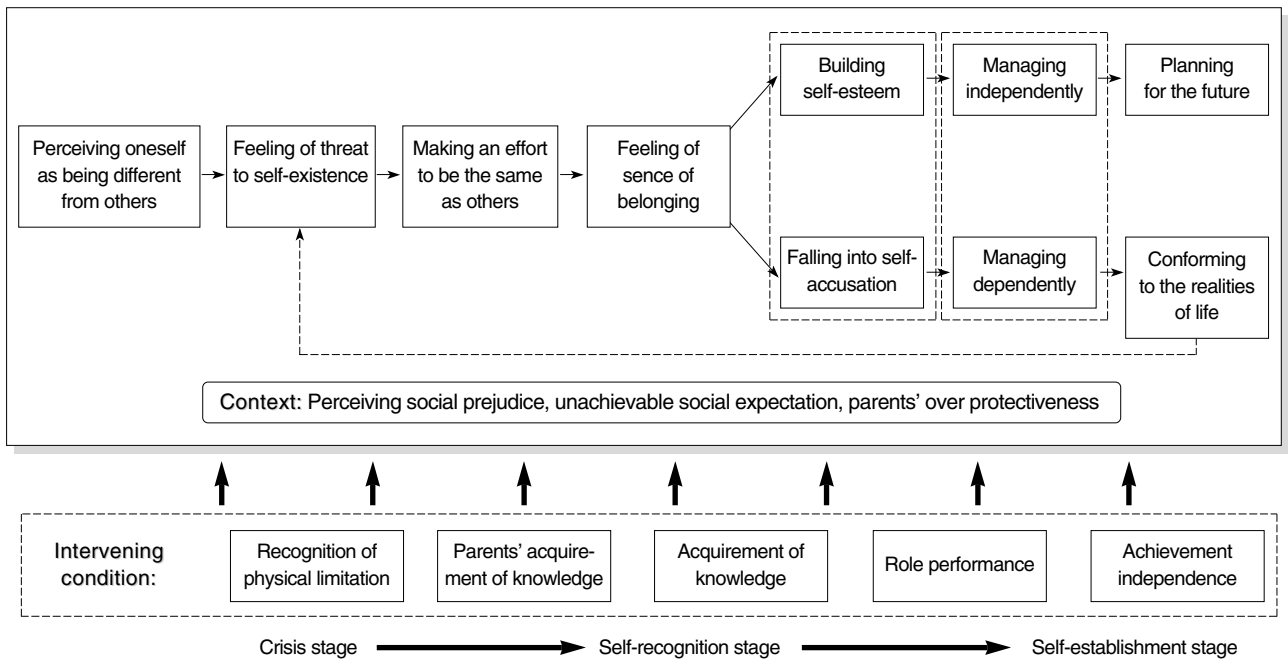


Figure 2. Journey to finding uniqueness of oneself as a person with CHD.

Spijkerboer (2006)

3) 자아정립의 단계

Berdat, Saner Carrel (2004) 14 . Immer, Althaus,

Kamphuis (2002) 18 32

3

논 의

1. 위기의 단계

. Lee (2000)

. Viner (1999)

(Erickson, 1980)

(Lee, 2000).

. 1986
 (Gutgesell, Gessner,
 Vetter, Yabek, & Norton, 1986), Swan Hillis (2000)
 19%

2. 자아 인식의 단계

. Deanfield (2003)

(Han & Kim, 2006; Lee,
 2007). Masi Brovedani (1999)

. Foster (2001)

(Berg-
 hammer, Dellborg, & Ekman, 2006)
 (Cabinno, 2001).

3. 자아 정립의 단계

. Branden (1992)

Uzark, vonBargen Mazza Messiter (1989)

, Kools, Gilliss Tong (1999)

. Cabinno (2001)

. Saunders Roberts (1997)

(Grown up congenital heart clinic, GUCH clinic)
(Deanfield et al., 2003).

결 론

3

REFERENCES

Berghammer, M., Dellborg, M., & Ekman, I. (2006). Young adults experiences of living with congenital heart disease. *International Journal of Cardiology*, 110, 340-347.

Branden, N. (1992). *The power of self esteem*. Deerfield Beach, Health Communication. Inc.

Cabinno, M. M. (2001). Health care issues facing adolescents with congenital heart disease. *Journal of Pediatric Nursing*, 16, 363-370.

Casey, F. A., Sykes, D. H., Craig, B. G., Power, R., & Connor Mulholland, H. (1996). Behavioral adjustment of children with sur-

gically palliated complex congenital heart disease. *Journal of Pediatric Psychology*, 21, 335-352.

Claessens, P., Moons, P., Dierckx de Casterle, B., Cannaearts, N., Budts, W., & Gewiling, M. (2005). What does it mean to live with congenital heart disease? A qualitative study on the lived experiences of adult patients. *European Journal of Cardiovascular Nursing*, 4, 3-10.

Deanfield, J., Thaulow, E., Warnes, C., Webb, G., Kolbel, F., Hoffman, A., et al. (2003). Management of grown up congenital heart disease. *European Heart Journal*, 24, 1035-1084.

Erickson, E. H. (1980). *Identity and the life cycle*. New York, NY: W. W. Norton & Co.

Foster, E., Graham, T. P., Driscoll, D. J., Reid, G. J., Reiss, J. G., Russel, I. A., et al. (2001). Task force 2: Special health care needs of adults with congenital heart disease. *Journal of the American College of Cardiology*, 37, 1176-1183.

Guba, E. G., & Lincoln, Y. S. (1981). *Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches*. San Francisco, CA: Jossey-Bass.

Gutgesell, H. P., Gessner, I. H., Vetter, V. L., Yabek, S. M., & Norton, J. B. Jr. (1986). Recreational and occupational recommendations for young patients with heart disease. A statement for physician by the Committee on congenital cardiac defects of the council on cardiovascular disease in the young, American Heart Association. *Circulation*, 74, 1195-1198.

Han, S. S., & Kim, K. M. (2006). Influencing factors in self-esteem in adolescents. *Journal of Korean Academy of Nursing*, 36, 37-44.

Immer, F. F., Althaus, S. M., Berdat, P. A., Saner, H., & Carrel, T. P. (2004). Quality of life and specific problems after cardiac surgery in adolescents and adults with congenital heart diseases. *European Journal of Cardiovascular Prevention and Rehabilitation*, 12, 138-143.

Kamphuis, M., Ottenkamp, J., Vliegen, H. W., Vogels, T., Zwinderman, K. H., Kamphuis, R. P., et al. (2002). Health related quality of life and health status in adult survivors with previously operated complex congenital heart disease. *Heart*, 87, 356-362.

Kools, S., Gilliss, C. L., & Tong, E. M. (1999). Family transition in congenital heart disease management: The impact of hospitalization in early adulthood. *Journal of Family Nursing*, 5, 404-423.

Lane, D. A., Lip, G. Y. H., & Millane, T. A. (2002). Quality of life in adults with congenital heart disease. *Heart*, 88, 71-75.

Lee, C. S. (2000). Influences of home environment, school environment and self-esteem on adolescent's ego-identity in Cheju. *Journal of College Education*, 2, 109-136.

Lee, E. S. (2007). Construction of a structural model about male and female adolescent's alienation, depression, and suicidal thought. *Journal of Korean Academy of Nursing*, 37, 576-585.

Lee, H., Kim, M. H., Jung, J. W., Kim, S. H., & Choi, B. Y. (2001). Prevalence of congenital heart disease from the elementary stu-

- dent heart disease screening program. *Korean Journal of Preventive Medicine*, 34, 427-436.
- Lee, H. J. (2001). Congenital heart disease after childhood experience of "grown up congenital heart clinic (GUCH Clinic)". *Korean Circulation Journal*, 31, 537-541.
- Masi, G., & Brovedani, P. (1999). Adolescents with congenital heart disease: Psychopathological implications. *Adolescence*, 34, 185-191.
- Saunders, C. P., & Roberts, G. J. (1997). Dental attitudes, knowledge, and health practices of parents of children with congenital heart disease. *Archives of Disease in Childhood*, 76, 539-540.
- Spijkerboer, A. W., Utens, E. M. W. J., De Koning, W. B., Bogers, A. J. J. C., Helbing, W. A., & Verhulst, F. C. (2006). Health related quality of life in children and adolescents after invasive treatment for congenital heart disease. *Quality of Life Research*, 15, 663-673.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research techniques and procedures for developing grounded theory* (2nd ed.). London: Sage, Publications.
- Swan, L., & Hillis, S. (2000). Exercise prescription in adult with congenital heart disease: A long way to go. *Heart*, 83, 685-687.
- Uzark, K., vonBargen Mazza, P., & Messiter, E. (1989). Health education needs of adolescents with congenital heart disease. *Journal of Pediatric Health Care*, 3, 137-143.
- Viner, R. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood*, 81, 271-275.