Enhancing the Clinical Patient Care of Adults With Congenital Heart Disease (CHD) by Understanding Family Planning Decisions in This Population

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Disclosures

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Learner Objectives:

1. Describe the Roy Adaptation Model as it applies to the CHD patient.
2. Examine how the CHD patient forms decisions regarding family planning.

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Background

Congenital malformations are the leading cause of infant death in US

Cardiovascular congenital defects affect 1% of all infants born in US regardless of race

(Hoffman & Kaplan, 2002; Xu, Kochanek, & Tejada-Vera, 2009)

Adult Incidence and Prevalence

Incidence: No standard reporting practices

Prevalence: 4.09 per 1,000 or approximately one million in the US

Median age: 40 years

(Canfield et al., 2006; Hoffman, Kaplan, Liberthson, & 2004; Marelli, Mackie, Ionescu-Ittu, Rahme, & Pilote, 2007; Warnes et al., 2001).

Severe CHD

Estimated 80,000 living with severe defects

1985: median age for those living with severe CHD was 11

2000: median age was 17

(Khairy, Ionescue-Ittu, Mackie, Abrahamowicz, Pilote, & Marelli, 2010; Marelli et al., 2007).

Mortality

2001-2009: Median age at death for all CHD was 48.8 years of age

2005: Median age at death for severe CHD was 23 years of age

(Khairy et al., 2010; Verheugt et al., 2010)

Purpose

To explore the personal narrative experience of adults with CHD and their family planning decisions.

Research Question

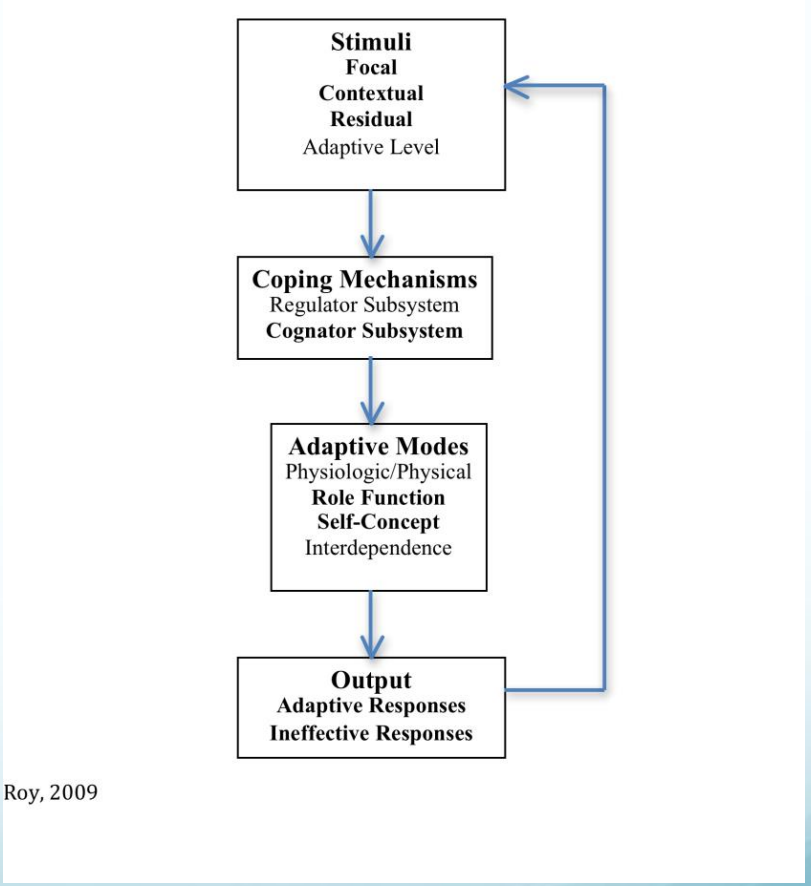
How do adults with CHD make family planning decisions?

Method

Qualitative Narrative Design

Roy's Adaptation Model

Recruitment



Roy, 2009

Sample

Final Sample

- N=17
- Age 24-41 years old
- Women living in 10 U.S. states

Data Collection

- Telephone Interviews
  - Took place over a period of 4 months
  - Average time per telephone interview – 43 minutes

Data Analysis

Narrative story

Structural analysis

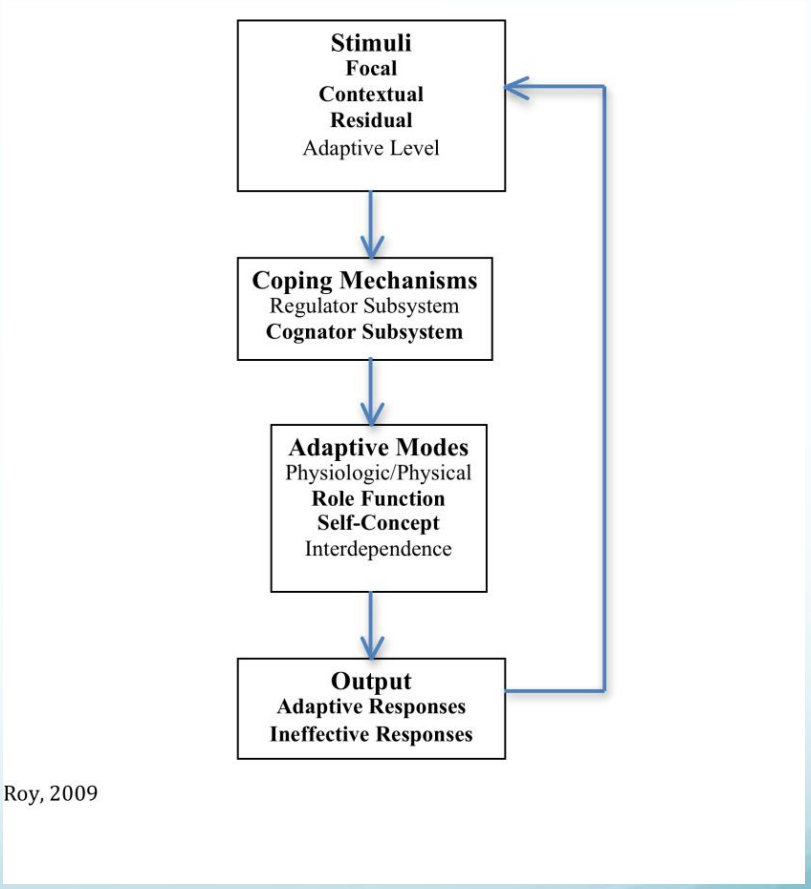
Thematic analysis

Roy Adaptation Model

Results

Stimuli – circumstances and influences that determine family planning – (focal, contextual, residual)

- **Wanting children**
- **Fear**
- **Family/friends pressure**
- **Committed, stable relationship**



Stimuli:
Wanting children

“I want kids because it is my passion to be a mother.”

Stimuli:
Fear

“The issue is survival. I mean, being blue and not having enough oxygen for myself...how am I gonna do it for two people?”

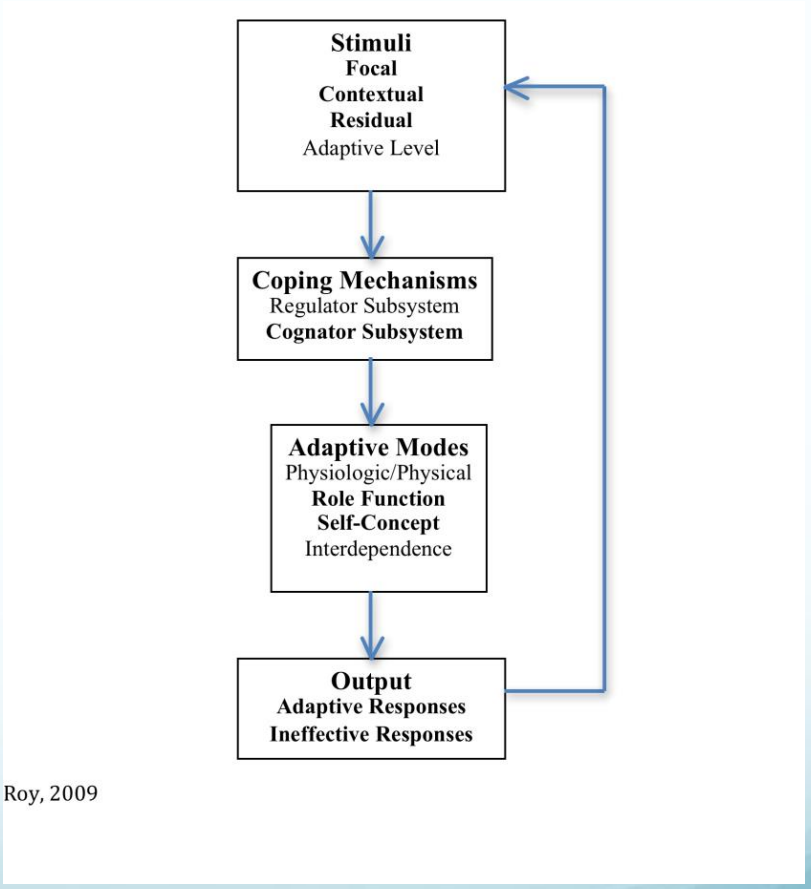
Stimuli: Family/Friends Pressure

“Everybody who thinks they should have a say is like, you are going to regret it if you don’t have kids.”

Results

Coping mechanism

Cognator subsystem- stores, relates, and responds to the stimuli through perceptual and information processing learning, judgment, and emotion.



Coping Mechanism: Cognator – Information Processing

“I looked up studies and I wasn’t excited about the outcomes. Not only is it a risk to your health, but there are not good outcomes for the child as well.”

Coping Mechanism: Cognator – Information Processing

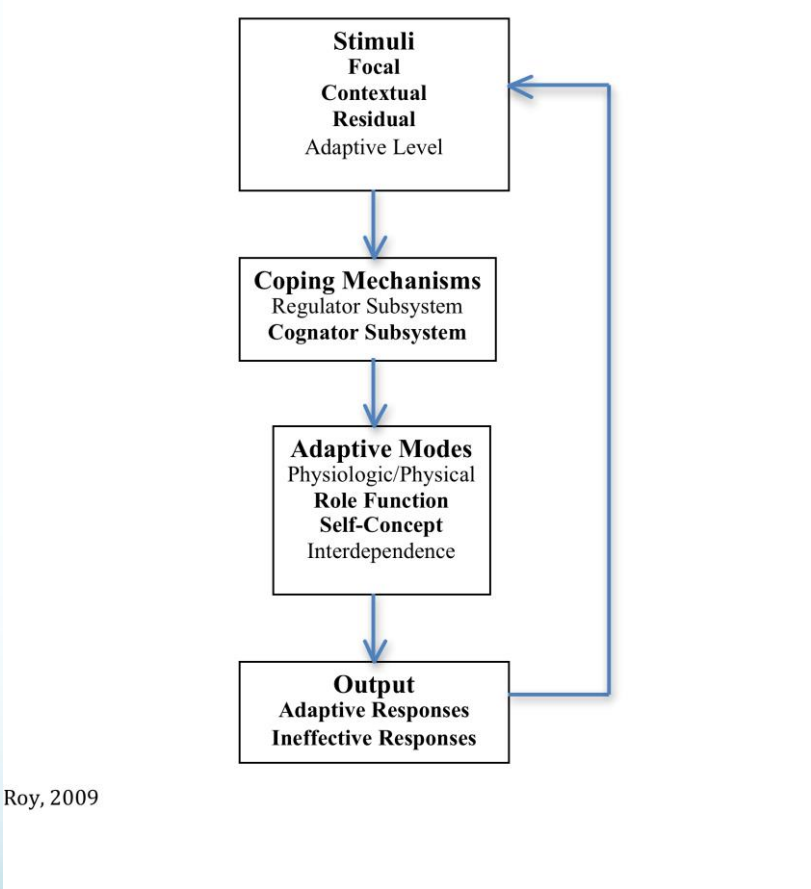
"We discussed adoption and surrogacy. So, we thought of different ways we could to have a child without me having to be pregnant."

Results

Adaptative modes

Role function – expected behaviors

Self-concept identity – beliefs about personal and self-ideal



Roy, 2009

Adaptive Modes: Role Function

“I didn’t have the same carefree attitude that my friends had. They just decided they wanted children and had their baby. It was just the normal fears and worries about having a baby. Not the kind of level that I had.”

Adaptive Modes: Self Identity

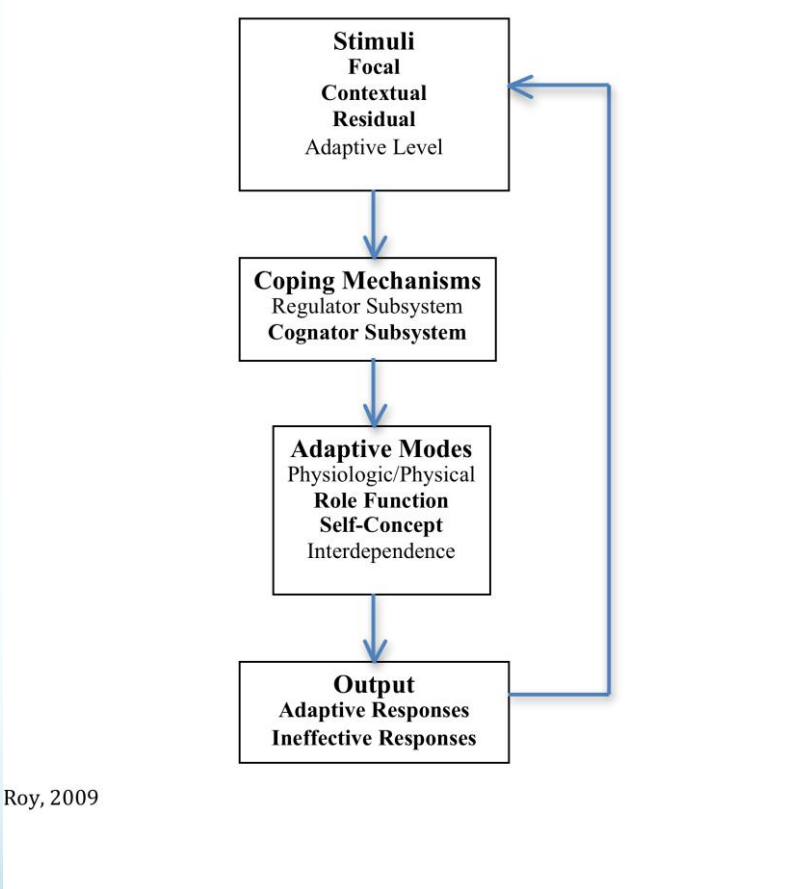
“I was trying to push through it (depression) without grieving, and then I realized I had to deal with that. I went through therapy, because it was hard to accept that I wouldn’t get to have that (pregnancy) experience.”

Results

Output behavior

Ineffective response – potential to threaten survival

Adaptive response – promote health and integrity



Roy, 2009

Output behavior: Ineffective Response

“I was told when I was a little kid that I would never walk and I have proved them wrong, I walk. And you know they probably think she can’t have a kid, but I want one.”

Output Behavior: Adaptive Response

“I am glad that I’ve already made this decision so I don’t have to think about things that would compromise my health in order to be in a fulfilling relationship. I feel secure knowing that is a closed book at this point.”

Conclusion

Family planning is an ongoing, emotional, difficult process.

Women in the study wanted early communication, accurate and reliable information, and support for their decision.

Clinical Implications

Family planning needs to be incorporated into primary care to address worries and concerns of the adult with CHD.

Future Research

Further evaluation of contraception, pregnancy, and childbirth including:

- Risk potential
- Counseling
- Complications
- Ethical dilemmas

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Discussion