

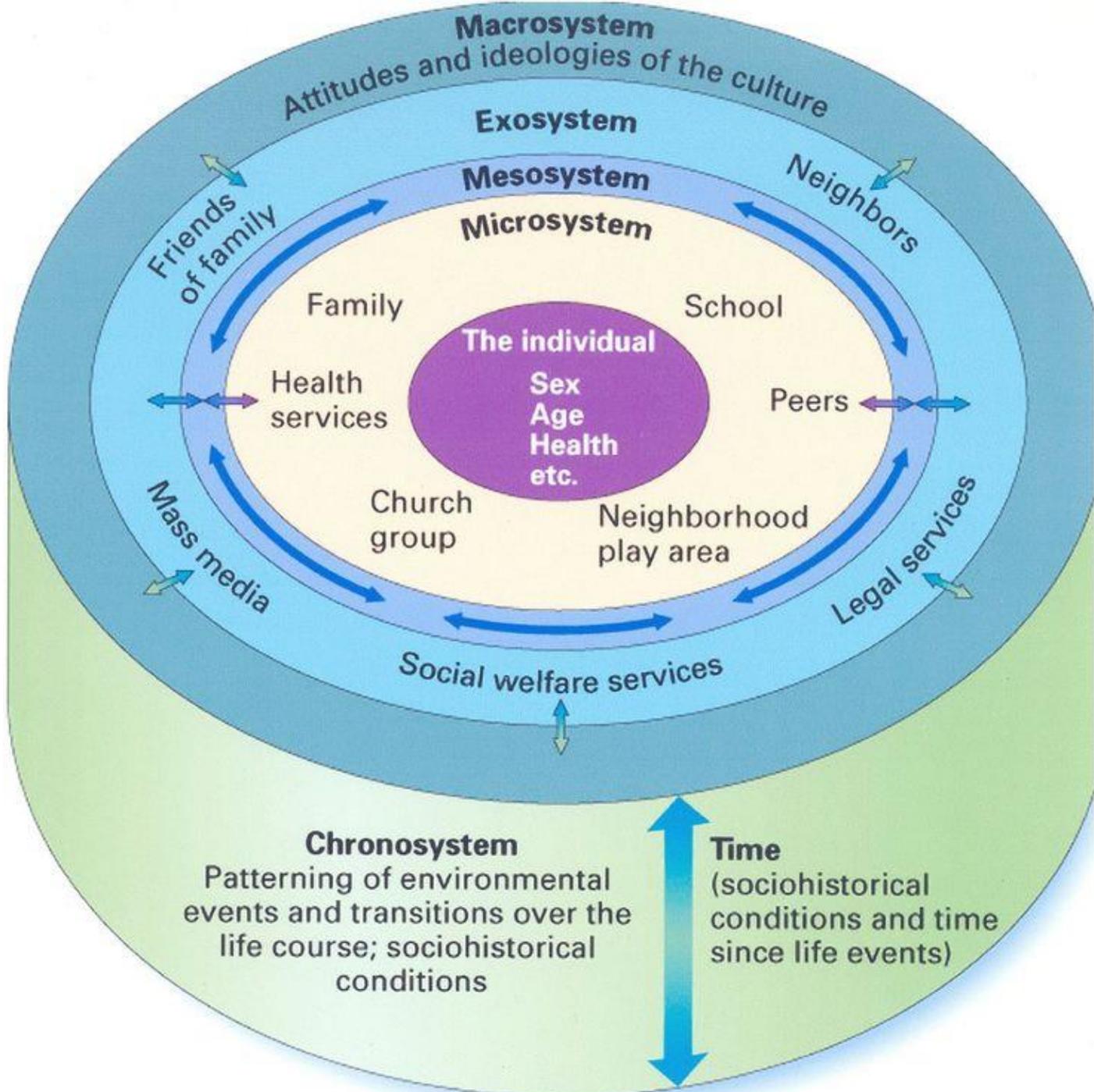


# IDENTIFYING AND MEETING THE PSYCHOSOCIAL NEEDS OF THE WELL SIBLINGS OF CHILDREN WITH CYSTIC FIBROSIS

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# SYSTEMS THEORY

“Each subsystem affects all other parts and the whole system.”

MYRA BLUEBOND-LANGNER

IN THE  
Shadow  
OF  
Illness

PARENTS AND SIBLINGS OF  
THE CHRONICALLY ILL CHILD

- “If he gets a cold I think he’ll go to the hospital and I get worried, because if he has to get something done to him that I don’t know of, I get mad because I don’t know what’s going on.”
  - Heather Farrington (ten-year-old sister of seven-year-old Casey)
- “Times when Carl’s sick, all the phone calls are ‘How’s Carl?’ Everybody who sees Stuart, ‘How’s your brother doing?’ And all the presents. Carl gets all the presents. It has to have some kind of effect on [Stuart].”
  - Deana Reynolds (mother of five-year-old Carl and seven-year-old Stuart)
- “I used to think that nobody cared about me, but now I can see why Casey is getting all the attention. It’s not because he is better than me. It’s just because he needs more of the attention than my brother and me. My parents are doing their very best for us all. I know our family will make it through the good times and the bad, if we just stick together.”
  - Evan Bailey (nine-year-old well brother of eight-year-old Casey)

# The Need for Intervention

- Well siblings of children with CF report worrying more, being jealous of the sick child, feeling lonely and anxious, having low self-esteem and experiencing difficulties in studies, play, or work
- Fewer social activities than their peers
- Emotional and concentration problems at school
- Consistently lower perceived quality of life
- Symptoms of PTSD
- Parent reports were more negative than child self-reports
- Needs evolve throughout the course of illness and treatment



# The Effects of Gender, Age, and Birth Order



- Siblings older than the child with CF scored significantly higher on the Negative Impact Composite
- Children older than the child with CF reported a greater impact on their quality of life
- Adolescent well siblings were more at risk for environmental influences than child siblings
- Females exhibit more internalizing symptoms while males exhibit more externalizing symptoms

# Risk Factors for Maladaptation



- Lower socioeconomic status
- The presence of emotional problems prior to the sibling's diagnosis
- Witnessing the teasing or bullying of their sibling
- Concurrent stressors

# Protective Factors Against Maladaptation



- Strong, positive family environment, especially parental stress
- Strong perceived social support
- Having a parent care for the well sibling when the child with cystic fibrosis is ill
- Being able to participate in the care of their sibling
- Maintaining a routine
- **Information from providers directly to well siblings**

# Potential Interventions

- Education
  - For parents: meeting the needs of the well sibling
  - For siblings: about cystic fibrosis, coping skills
- Support group
  - All participants reported reduced feelings of isolation, and increased communication and friendships
  - Refer to online support groups



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