

Issues of Maturity and Life Stage Conflicts in People with Cystic Fibrosis

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Abstract

People with a reduced or uncertain life expectancy, such as those with cystic fibrosis (CF),¹ express the concerns associated with Erik Erikson's later life stages (middle and late adulthood) much earlier and often simultaneous with earlier age-appropriate issues. This call to maturity is the result of a need to make a meaningful life in a shorter span of time, the high level of personal accountability in the day-to-day treatment of CF, and the need to develop enhanced coping mechanisms in the face of adversity. Social workers must be aware of and sensitive to the struggles of a person with CF dealing with the issues of multiple life stages simultaneously and the pressure to exhibit extraordinarily mature behavior and insight.

¹ Cystic fibrosis (CF) is a genetic disease that causes malnutrition and a constant build-up of mucus in the sinuses and lungs, which over time are infected with more damaging and antibiotic-resistant strains of bacteria. At the beginning of the twentieth century, newborns suspected of having CF rarely lived beyond infancy. Today, the average life expectancy is 37 years, due to digestive enzyme supplements, more sophisticated antibiotics, mucus clearance devices and techniques and, increasingly, gene-based therapy.
<http://cysticfibrosis.about.com/od/cysticfibrosis101/f/lifeexpectancy.htm>

I am 22 years old. I am married, finished with school, work full-time, and we are planning on trying for children in the next year or so. In fact the only reason that we aren't already trying for children is financial reasons.

I have been told many times that I am very mature for my age. After all, a lot of people my age are still partying, drinking and generally screwing around.

Even in high school, I was never really interested in going out and partying. I went out with friends, went to dances, and had boyfriends, but I also made it a priority to spend time with my family.

I think that because I most likely will have a shorter time in this world to experience and appreciate the truly wonderful things in life. For me, these things are friends, family, and having a life that I can be proud of before I don't have the chance anymore.

Marisa RN, 22w/CF

i had to understand at the age of 5 why i'm being poked on all the time..why i have to take so many pills..why i'm in the hospital..I'm 24 with cf.i got dx when i was 6 months old.i have had not a normal childhood,And no relationships b/c my girlgriends think i'll die on them..Can't really work b/ my health ...

24 male with cf in oklahoma dx at 6 weeks old

During the course of more than two years of observation and participation in a message board for people with cystic fibrosis, www.CysticFibrosis.com, I have seen thoughts, behavior and activities that are inconsistent with what is considered “typical” for adolescents and young adults.² Young people with CF often exhibit the concerns of middle and late adulthood as defined by Erik Erikson (as cited in Hutchison, 2008, p. 116). These concerns or conflicts are generativity vs. stagnation and integrity vs. despair, and in people with CF, they are found simultaneous with age-appropriate life stage concerns of identity vs. role confusion and intimacy vs. isolation. From the moment of diagnosis, which is often at birth, CFers (this designation seems to be accepted in the community) are asked to develop a high degree of personal accountability because of their treatment regimen and must struggle to attain the mature coping mechanisms described by George Vaillant (as cited in Hutchison, 2008, p. 347). This accountability

² This is a self-selected group with access to computer technology and enough willingness to confront their disease that they surf a website dealing with it.

can be seen in the writing of the 22-year-old, Marisa, quoted above; and the struggle to cope at an early age can be seen in the writing of the 24-year-old male also quoted above.

On the message board, there are many threads that deal with life-stage appropriate concerns. Specifically, CFers in their late teens through thirties can be found questioning their identity and how much of it is defined by their disease, religion, profession; expressing a sense of isolation from healthy people because of their CF or celebrating a sense of solidarity with other CFers; and discussing the impact of career and family-planning choices. These are all topics that agree with Erikson's stage of young adulthood. However, side by side with the above-mentioned conversations are threads by the same people discussing whether a much coveted career is now threatening one's health, how to preserve quality time with loved ones, how to stay motivated about doing time-consuming treatments in the face of a continued decline in health, whether to create a child knowing that it may lose a parent before reaching adulthood, how CF has enriched or burdened one's own life and the lives of loved ones, and what CFers are doing to improve the chances of younger generations of with CF. Even removing the CF component, these threads express concerns not typical of people in their late teens through thirties. The early recognition of one's mortality often results in concerns more typical of middle and late adulthood: the need to make meaningful connections, contribute to the next generation and see personal and communal accomplishments (Erikson, as cited in Hutchison, 2008, p. 116). However, CFers rarely have the years of experiences that Erikson describes: taking care of aging parents, ending a long career; and therefore their conflict experience is unique and must be treated as such.

The daily regimen of care for CF also demands an abnormal degree of maturity in CFers. Treatment is handled by the patients themselves often by the time they are teenagers. This includes being careful to eat high fat, high calorie foods, taking digestive enzymes at appropriate times, doing multiple hours of nebulized medications and airway clearance every day, exercising for thirty minutes a day to build strength, getting enough sleep and avoiding lung irritants that could exacerbate an infection. The CF treatment regimen is unyielding. Even when a person is not actively sick, it is a necessary preventative measure. CFers often speak of a rebellious period in their teens or later when they skipped treatments because they wanted to feel normal or were being "lazy." When people with CF fail to adopt an extraordinarily mature approach to their treatment, family members may try to step in to act on their behalf possibly creating additional tension and rebellion.

People with CF have different disease severity and differing mental resources for dealing with adversity and stress. But universally, the disease demands mature coping mechanisms. In addition to mature life-stage conflicts and mature lifestyle requirements, young CFers struggle to develop coping mechanisms ahead of their biological maturity. From an early age, CFers deal with long hospitalizations, illness and procedure-related pain, and exclusion from activities depending on health status. Some of the mature coping mechanisms described by George Vaillant (as cited in Hutchison, 2008, p. 347) are evident on the forums. *Mature humor*: There are painfully hilarious threads of the sort “You know you have CF when...” with hundreds of messages. *Sublimation & Suppression*: People share experiences of modifying, cancelling or postponing education, travel, and social plans because of CF-related outside their control.

Social workers, mental health professionals and even family and loved ones should recognize that CFers deal with internal conflicts typically associated with older adults, and pressures toward maturity that are outstanding for any age. People with CF deal simultaneously with age-appropriate conflicts and with the conflicts associated with an older biological age, usually without having all the experiences of an older person. The condensing and overlapping of life stages results from the uncertain and shortened life expectancy of a person with CF. Further movement into older life stages can be caused by the development of mature coping mechanisms and the personal responsibility required by the daily treatment regimen. CFers vary in their abilities to achieve this maturity, to cope with adversity and to be accountable for daily treatments. Social workers must be aware of these issues as well as their profound influence on the health of the CFer.

Hutchison, Elizabeth D., (2008). *Dimensions of Human Behavior: The Changing Life Course*. Los Angeles: Sage Publications, Inc.