

Normalization, Chronic Sorrow, and Murder: Highlighting the Case of Carol Carr

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As parents of special needs children, we are taught that we should be normalizing our experience with time. "Normalization remains the clinical standard used to judge effectiveness of family management. Families who have members with chronic conditions are urged by health care professionals to construct their lives and interactions as close to 'normal' as possible" (Deatrack, Knafl, & Murphy-Moore, 1999, p. 3). Knafl and Deatrack have long written about parents of children with osteogenesis imperfecta and diabetes who though initially devastated by their children's conditions, learn to adjust and become a normal family.

Family researchers such as Eakes, Hainsworth, Lindgren, and Burke (Eakes, Burke, & Hainsworth, 1998), however, came up with a different set of results from their research. Chronic sorrow is their descriptor of families whose grief may abate and renew as developmental milestones are missed and as the differences of their children isolate them from the mainstream parenting experience. Chronic sorrow involves a disparity between the expected trajectory of parenting and the actual life led.

Obviously, how well the child does influences how well the family does. But even Knafl and Deatrack (2002) later found that the parents who were not normalizing as expected were those whose children had experienced dips in their conditions and had not stabilized over the years. Helen Harrison, long time speaker for the rights of parents to speak out honestly about the "bad hand that has been dealt to them," discusses these issues in her recent article called "Making Lemonade, Parents Speak out about Quality of Life Studies." Harrison (2001) describes how parents of children with impairments often feel obliged to lie to friends and family, to pretend that life is fine, that parenting a special needs child is not difficult, and that life at home is normalized. She discusses the irrational guilt these parents may feel for being the "agent of the damaging conditions of their [children's] births." Harrison reports that parents who dare to discuss the negative aspects of their situations are often accused of

being "bad parents" or "prejudiced against the handicapped."

Researcher S. Saigal, a neonatologist who has done follow-up quality of life studies of impaired NICU graduates in Canada, and colleagues (1999, 2002) depicted the life of children with special needs as positive, with more impaired NICU survivors giving themselves perfect quality-of-life scores than did a control group of full-term, non-impaired children. When Saigal's results reporting how well the impaired children were doing were published in JAMA, a cry rose up from parents of disabled children around the world. Ten of them wrote a lengthy response to Dr. Saigal, which was printed in the JAMA letters to the editor (Culver et al., 2000). This is an excerpt:

In response to Dr. S. Saigal: "We say you must look at surviving children who are experiencing months or years of grueling hospitalization with associated gastrostomy tubes, jejunostomy tubes, funduplications, tracheostomies, shunts, orthopedic, eye, and brain surgeries, hyperalimentation, oxygen tanks, and ventilators ... including [family] bankruptcies, divorces, mental and physical breakdowns, deaths in late childhood, neglected siblings, and suicides caused by the extreme burdens of caring for severely mentally and developmentally compromised children." Parents Culver, Fallon, Londner, Montalvo, Villa, Ramsey, Ramsey, Treboal, Houle, Williams, Williams, and Wolding.

Trying to normalize in the face of ongoing impairment of one's child is the backbone to the discussion of the case of Carol Carr. Carol Carr, 63, was arrested in June 2002 for the murder of her two adult children, Randy Scott, 42, and Andy Scott, 41, as they lay in their beds in the Sunbridge Care and Rehabilitation Center in Griffin, Georgia. Randy and Andy, as well as Carr's husband Hoyt, his brother George, his sister Roslyn, and their mother all suffered from severe deteriorating Huntington's Disease (HD), and Carr's third son, James, has begun to show signs of the disease. HD left the Carr family members with tremors, mood swings, and the inability to walk, talk, swallow, or care for themselves in any way. Carol Carr cared for her husband for 18 years until his death and her three sons were also diagnosed with the disease. Her husband's brother, George, killed himself in her home when his involuntary movements caused him to be fired for spilling oil all over cars at his gas station job. In 1995 all three sons signed living wills asking for no extraordinary care to keep them alive (Scott, 2003).

Carr cared for her sons at home for many years. She gave their meds, fed and bathed them, and took them to doctor's appointments. "She went to extraordinary lengths to care for them," stated neighbor H. Sampson (CNN, 2002). When son Randy began having violent rages and striking out, she was no longer able to provide the care herself. Randy and Andy were placed in a nursing home

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Other "Mercy Killings:" Cases in Which Parents Felt Their Children Had Experienced Enough Suffering and Assisted in Ending Their Lives

1988: Chicago, Illinois

Rudy Linares, father of Samuel Linares, entered the PICU at Rush Medical Center and held a magnum .357 to the nurses, stating that he would kill anyone preventing him from disconnecting his son's ventilator. Samuel, after choking on a balloon at a birthday party, had been diagnosed as in a persistent vegetative state. The hospital would not allow the ventilator discontinued without a court order. Rudy Linares disconnected the ventilator then waited for the police to arrest him. Outcome: The Chicago grand jury refused to indict the father for homicide.

1988: Cobb County, Georgia

Barbara Monroe, mother of 32-year-old Gail Terrell, shot her daughter in the back with a .410 gauge shotgun. Gail suffered from epilepsy and cerebral palsy and had recently moved into a house three doors down from her mother so that her mother could care for her. Outcome: Monroe pleaded guilty to voluntary manslaughter and was ordered to serve 5 years of a 20-year prison sentence.

1993: Saskatchewan, Canada

Robert Latimer, a Canadian farmer, put an end to his 12-year-old daughter Tracy's life by sitting her in the cab of his truck and connecting a hose of carbon monoxide. Tracy functioned at the 3-month-old level; was quadriplegic; weighed 40 pounds; could not walk, talk, or feed herself; and was said to be in constant pain. Outcome: Robert Latimer has been twice tried for his daughter's death, lastly convicted for second degree homicide, and is serving a 10 year sentence with no possibility of parole. This case caused great outcry by disability activists.

1994: Ontario, Canada

Cathie Wilkieson, 43, mother of Ryan Wilkieson, 16, was found dead in her garage from exhaust fumes. In her arms was her son Ryan, who had cerebral palsy and was deaf and blind. A note beside her stated that she "could not go on any longer and could not leave him behind." It is reported that Wilkieson had been denied respite services a few weeks prior. Outcome: Disability activists have been outraged over this copycat mercy killing shortly after the Latimer case went to trial. This case led Canadian ethicists to coin the term "altruistic filicide."

1994: Lansing, Michigan

Dr. Gregory Messenger, a dermatologist, removed his extremely premature son from a ventilator in the Sparrow Hospital neonatal intensive care unit and held him in his arms until he died. The newborn infant had been placed on mechanical life support despite the explicit instruction of the parents that they did not want aggressive or resuscitative measures used on their 780 gram, 25 weeks gestational age son. Outcome: Gregory Messenger was found not guilty of manslaughter charges, and the jury found him innocent of breach of his legal duty to provide proper medical treatment for his son.

(Rimer, 2002). Carr visited regularly yet prayed that somehow her sons would be put out of their misery. Unconfirmed reports state that the boys actually purchased the gun that Carr used to shoot them for shooting themselves when the time came, and psychologist Catherine Boyer testified in court that the boys had previously attempted suicide by swallowing 50 tablets each of the tranquilizer Tranzene (Atlantic Journal Constitution, 2003).

James Scott described visiting his brothers and finding them "lying in their pee, mumbling, and staring at the ceiling" (Hewitt, Westcott, & Truesdell, p. 64, 2002). During the week of June 8, 2002, Carr tried to obtain more care for her sons whose beds had not been changed in several days. One son, Andy, had now been catheterized and was trying to pull the catheter out. "He just looked at me with his eyes and I knew he was asking me for mercy," stated Carr (Karras, Torpy, & Scott, 2002).

On June 8, Carol Carr walked in to the nursing home to visit as she did several times a week. This time, however, she shot each of her sons in the head with a small .25 caliber pistol. She then called the police and sat calmly in the waiting room until they came to take her away. "I did it," she told the arresting officer. James Scott, brother to Randy and Andy, calls the deaths of his brothers a "mercy killing."

The arrest of Carol Carr and the charge of murder brought out activists of all sides. "We fear for our lives and the lives of other disabled people," stated Eleanor Smith (Beverly, 2002), representing the advocacy group Not Dead Yet of Georgia. "There is no such thing as mercy killing; murder is murder," stated Rebecca Ramage Tuttle of the group Disability Link (Macon Telegraph, 2002). Other HD caregivers stood in support of Carr. Mary Anderson, whose father, sister, and two brothers died of Huntington Disease, pledged solidarity to Carr. "She is just as much a victim of this disease as her sons were," Anderson stated (LeHay, 2002).

Carr was charged with murder, denied bail, and incarcerated in the Spaulding County jail. She told the arresting officers that Andy had just "pleaded with her with his eyes" and she could not take it anymore (Karras et al., 2002). She had promised to keep them from suffering. James Scott said of his brothers' deaths, "I don't think they died last night. I think they died a few years ago. Their lives were over then" (Scott, 2002).

For 7 months Spaulding County was the focus of attention for rallies in favor of freeing Carr and for demonstrations against her. The prosecuting attorney, William McBroom, stated that there were people calling him and chastising him for prosecuting and others calling and telling him he should hang Mrs. Carr (Atlantic Journal Constitution, 2003).

On January 20, 2003, the Carr case came to the courtroom. To the surprise of many, a plea agreement was reached. Lee Sexton, defense attorney, was able to reframe the murder charges into assisted suicide. Assisted suicide is also punishable by law. Carr was sentenced to 5 years in prison. There are stipulations regarding her release. She cannot live with her son James and is forbidden to be his caretaker.

Although as health care providers we might have expected Carol Carr to normalize, Carr did not. "How could I go to a movie ... when my sons were lying there in the fetal position?" (Robertson, 2002). The chronic sorrow that she experienced is recognizable. Questions about the care of chronically ill children remain. Why are there nursing homes without enough staff? Why should patients be allowed to lie in unchanged beds and develop decubiti as the Carr boys did? JoAnne Lynn, MD, Director of Americans for Better Dying, describes the physical and emotional toll of caregiving those with HD. Families "face severe financial challenges, inade-

quate skilled nursing care, and diminished social support" (Lynn & Lampson, 2002). Lynn, in writing about the Carr case, stated: "If we were a caring society, she (Carol Carr) would have had the confidence that she and they would live out lives of reasonable comfort and support, networked with people who care for them."

The Carr case and those of other parents who have been arrested for causing the deaths of their children (see Sidebar) raise numerous questions that have come about since the ability to provide life extending ventilatory support and artificial feeding to marginally viable children and adults. Paris and colleagues (2001) and Smith and Uphoff (2001) raise numerous questions about extensive and extraordinary care and the outcomes for children and families of that care. As health care providers, we must question assumptions about normalization and whether it is always possible and about mercy killing and if it is ever supportable. As we continue to advance in our methods of technologically-supported life, these questions will not lessen, but only increase for nurses, health care providers, and those we serve.

Recommendations for Support for Families with Huntington's Disease

Huntington's Disease Society of America

The Huntington's Disease Society of America (HDSA) is dedicated to finding a cure for HD while providing support and services for those living with HD and their families. HDSA promotes and supports both clinical and basic HD research, aids families in coping with the multi-faceted problems presented by HD, and educates the families, the public, and health care professionals about HD. The Web site is www.hdsa.org

HD Lighthouse

The HD Lighthouse is a site that provides news and research updates for persons with HD. It is an informal news site moderated by Jerry Lampson. This site monitors all recent research and treatments and is intended to assist proactive treatment and care of HD. The Web site is www.hdlighthouse.org

Huntington's Disease Advocacy Center

The Huntington's Disease Advocacy Center (HDAC) is a Web site for those who have HD or who care for someone with HD. The goal is to help caregivers, families, and patients with HD by supplementing information that a neurologist, physician, or psychiatrist might provide. A forum is provided for those who have offered to share experiences regarding issues such as feeding tubes and nursing home placement. Access the Web site at www.hdac.org

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