



Bump. Bump. Bump.

The music carrying from the radio seems to mimic the rhythm of the black leather seats – warm from the sun beating through the glass, begging to enter. The content of the music is lost on the driver – it’s always just background noise to a mind lost in whirlwind thoughts and future plans. Beside the driver sits a form of matted, thread-bare fur aged by affection and attention – weighed down by mysterious beans extending into hands, feet, and a precious (well-kissed) rump. A stained checkered ribbon acts as a distinguished bowtie for the passenger. Chilled air from the AC fights to blow through the fur but becomes as tangled as the hair it tries to rustle while simultaneously chilling dark plastic eyes.

Both passengers are safely buckled in by tan nylon ropes – obviously equally precious cargo – and lost in the monotonous movement of the vehicle traveling down the patchworked roads of the South. Merging has become second nature – swaying along the streets as if following a white-capped river. Both heads are cocked to the left as yet another armored tank comes into their periphery, reflecting the sun from the chromed grill and each of the 18-wheels reaching the height of the car passengers. Except something is different this time.

Chronic pain can originate from almost anywhere. Some are born with genetic conditions that carry consistent painful flareups, others are involved in life changing accidents that leave behind a daily reminder of the incident, and others are plagued by psychologically debilitating pain. While living with this pain already breeds a set of overwhelming challenges, some must navigate life with chronic pain combined with the trials of parenthood. One of the least understood and most understudied aspects of this dynamic is how such chronic pain affects children of disabled parents, if at all.

The passenger seat teddy bear escaped without change. Perhaps it's that consistency that has made him such an imperative source of comfort for so many years. My father was the driver – run off the road by an 18-wheeler and into a head-on collision with a tree. He was not as lucky as my unchanged teddy bear.

My father has lived with chronic pain every day since. Parents with chronic pain often report higher levels of depression and anxiety as compared with parents without such pain. This can be attributed to the toll that living with consistent debilitating pain and lack of future relief brings. The studies that have been conducted on the effects of parental chronic pain have chosen to focus on the mental health of the children. Research has found that many children of such parents tend to adopt similar mental health outlooks as their parents.

Children of parents with chronic pain seem to have higher rates of anxiety and depression. One such cause for this finding is that adolescent children of parents with chronic pain often feel “torn between their newfound autonomy and the need to stay home during a crisis” (Kasboll, 2012). This results in internal turmoil for many children with the conflict of choosing between personal autonomy and the care of their parents.

I wish Ted had a more interesting backstory – one other than being given to me as a gift one random summer day by a family friend as I sat on kitchen countertops “helping” my dad cook dinner. I gave Ted to my dad just moments before he left on his trip. I wanted him to have a guardian angel by his side, the same one that was beside me during surgeries and restless nights. Nights where my mind was occupied by things that now seem painfully insignificant. I received countless pictures of Ted on that trip with my dad. At the gas station, at restaurants, sitting on the hotel bed, up until the day of the accident.

I didn't understand the importance of the car accident at the time it happened or the effect it would have on me. My father was in the hospital – the safest place he could be. No visible signs of injury – no cuts, scrapes, bruises, or broken bones. I didn't understand why it was such an important event with people surrounding his hospital bed and my mother quietly crying. My teddy bear didn't change, so why would my father have?

Disability is such a strange thing. It drastically shifts lives yet is entirely unseen. It only becomes visible through change. The sudden change of my father perpetually stuck at home, sometimes as stiff and unmoving as his faithful passenger. The sudden litany of pill bottles skewed across the bathroom counter – with labels as difficult to read as a foreign language. The change in my father – his demeanor, his attitude, his life, but not his love.

A common reason for children of parents with chronic pain to experience mental health symptoms is the anticipation of future loss. Children quickly learn that their parent's illness will likely not be remedied and reflect on the fact that their health may continue to deteriorate or that their own health may follow in their parent's path (Umberger, 2015). In fact, many children of parents with chronic pain report higher levels of pain themselves. "One-third of children of mothers with chronic pain reported pain in a site identical to their mother and almost half of the children of fathers with chronic pain reported identical pain to their fathers" (Evans, 2007).

Despite the findings that children may internalize the pain experienced by their parents, chronic pain does not produce poor parents. Multiple studies have found that children of parents with chronic pain experience more flexible family roles, identification of external obstacles as barriers to family functioning rather than blaming parental disability, greater problem-solving skills, enhanced coping skills, greater acceptance of difference, and more positive attitudes towards disability (National Council on Disability, 2022). Furthermore, the resilience of children

can be readily seen through the coping mechanisms that lead to an early understanding of the value of family and friends, finding humor in dark situations, and putting problems in perspective (National Council on Disability, 2022).

Although I would describe disability entirely differently now as compared to my seven-year-old self, it still doesn't have a clear definition. It's so vastly diverse for every person that endures it and even further from understanding for those that experience it through their loved ones. The one constant that has remained throughout my life is my teddy bear, who joined my father on his car ride and has joined me throughout my life. The accident left him unchanged, unharmed. Although disability seems to change almost every aspect of life, it's the things that remain the same that reveal their lasting importance.

Ultimately, children of parents with debilitating chronic pain experience a life that differs from their peers in a multitude of ways, but not all of these differences are negative. Families experiencing chronic pain place the relationship between parents and child into new, and important, perspectives that can be beneficial for other families to observe.

It wasn't until he came home and I began to age surrounded by changes caused by the accident that I realized disability could be a word as heavy-handed as death. An unmoving constant that was now in our lives. I so desperately wanted to "cure" his spinal injury with methods that now reveal themselves to be innocent imaginings of a mind unable to comprehend an illness outside the scope of medical solutions. My teddy bear came back safe and sound, protected by my father's love and care for something I held so dearly. Surely, all a spine needs is a circle of stuffed animals surrounding my father, as I lay in his arms and declared my hopes and dreams for the future – the same track of mind he once held as closely as he held me.

References

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