



“It didn’t kill me. It just made me stronger and wiser”: Silver Linings for Children and Adolescents of Parents with Chronic Pain



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ABSTRACT

Chronic non-cancer pain (CNCP) is a disease that affects adults in their child-rearing years and is often incurable and of indefinite duration. Children and adolescents who live with parental CNCP can endure multiple adversities and experience subsequent emotional and somatic difficulties. Resilience is the ability to overcome adversity and even experience growth. This study is a secondary analysis of qualitative data, which sought to gain a deeper understanding of the ways in which children and adolescents rebound and grow from experiences living with parents who suffer with CNCP. Young adult children (N = 30) of parents with CNCP were interviewed. Content analysis yielded five ways in which their experiences led to areas of positive growth: (a) expanded ways of understanding; (b) cultivated a strong character; (c) aided in the development of important skills; (d) instilled a commitment to live well, and; (e) nurtured spirituality. Clinicians who work with children and adolescents whose parents are disabled with CNCP can create environments that foster resilience and serve as a guide by helping these youth recognize potentials that have not yet been actualized and promoting positive change and growth over time.

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Over the past four decades, researchers have advanced increasingly complex models for describing and studying resilience in youth who overcome adversity (Bonanno & Diminich, 2013; Masten, 2011; Masten & Tellegen, 2012; Scoloveno, 2015). The most recent conceptualization specifies that resilience is the “capacity of a dynamic system to withstand or recover from significant threats to its stability, viability, or development” (Masten, 2014, p. 6). Most contemporary models of resilience require that two conditions be met. There must be evidence of some sort of significant risk or adversity in the life of a person, which increases the probability of a negative outcome(s). Then, positive adaptation must be demonstrated by the person in spite of the risk or adversity (Shiner & Masten, 2012). Several resilience pathways have been described illustrating either: (a) stress resistance or a pattern of little disturbance in functioning; (b) breakdown and subsequent recovery of function, usually in response to a sudden, overwhelming stressor, and; (c) growth or improvement of functioning (Bonanno & Diminich, 2013; Masten, 2014; Masten & Tellegen, 2012). Current models of resilience also propose that resilience promotes hope, well-being, and health promoting lifestyle in children and adolescents (Scoloveno, 2015).

Resilience in the midst of a wide range of aversive childhood life events has been the focus of many studies – adversities such as

maltreatment (Ciccetti, 2013), chronic illness (Boles, 2013), institutionalization (van Ijzendoorn et al., 2011), and exposure to extreme poverty (Flouri, Tzavidis, & Kallis, 2010) and violence (Howell, Graham-Bermann, Czyz, & Lilly, 2010). Research on resilience in children living with adversity related to parental illness focused on those whose parents were diagnosed with HIV/AIDS (Betancourt, Meyers-Ohki, Charrow, & Hansen, 2013), mental illness (Fraser & Pakenham, 2009), and substance abuse (Moe, Johnson, & Wade, 2007). To date, there have been no studies exploring resilience in children and adolescents living with parents suffering with chronic non-cancer pain (CNCP) – a disease that is experienced by adults in their child-rearing years and is often incurable and of indefinite duration (IASP, 1986; Merskey & Bogduk, 1994).

A recent report by the Institute of Medicine (2011) asserts that over 100 million Americans experience pain on a daily basis. Findings from recent studies (Umberger, Risko, & Covington, 2015; Umberger et al., 2013) show that children and adolescents who live with parents that are disabled with CNCP endure multiple hardships and adversities, such as assuming adult roles before they are ready and able, blaming self and taking responsibility for parents’ pain and disability, and managing day-to-day activities in the mist of parents’ co-morbid mood changes. Parental CNCP has also been linked to a number of subsequent emotional and somatic difficulties in children, such as externalizing and internalizing disorders and increased pain complaints (Umberger, 2014). The purpose of this study was to explore resilience and growth in children and adolescents who lived with a parent experiencing CNCP. Research questions are: (a) Is there evidence of resilience and growth in children and adolescents who lived with parents suffering

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with CNCP? (b) How is resilience and growth described? (c) Do male and female participants' perceptions of their resilience and growth align?

METHODS

In a previous grounded theory study that explored adolescents' perceptions of how they managed living with parents experiencing CNCP (Umberger et al., 2013, 2014), "resiliency and positive outcomes in adolescents living with parental CNCP" were identified as an important phenomenon for future analyses. This study utilized a secondary analysis of 30 transcripts from the original grounded theory data, the purpose of which was to gain an understanding of resiliency and growth in children and adolescents growing up in a home with parental CNCP.

Sample

Young adults, between the ages of 18 and 21, who identified having lived, during their adolescence, with a parent suffering with CNCP were recruited in the original grounded theory study. In this targeted age range, participants were able to reflect on their adolescence in its entirety without being far removed from their adolescent experiences. Study announcements were posted in public sites in community settings and on the American Chronic Pain Society website. Those who were interested in participating were screened to determine whether the criteria of age (18 through 21) and having lived with a parent with CNCP during adolescence were met. The sample was recruited over a 2-year period and ended when the research team recognized that saturation occurred and new participants' accounts became redundant. Both purposive and theoretical sampling were used to recruit a diverse sample (e.g., gender, race) and ensure understanding of emerging theoretical constructs across a range of conditions.

The final sample size was 30 participants; data from all 30 participants were used in the secondary analysis. The sample included 21 females and 9 males whose ages fell within the 18–21 year criterion. The majority of sample was Caucasian ($n = 21$), followed by African American ($n = 5$), Asian ($n = 3$), and American Indian ($n = 1$). Nineteen participants described living with a mother suffering with CNCP, while the remainder of the sample ($n = 11$) described experiences living with a father with CNCP. The mean parental pain duration was 140 ($SD = 69.07$) months. Twelve participants indicated that parental pain was due to some form of arthritis; 6 from fibromyalgia; 5 from migraine headache; 4 from herniated disc; 3 from degenerative joint disease; 3 from neuropathy; 3 from fractured vertebrae; 2 from carpal tunnel; 2 from Crohn's disease; 1 from chronic regional pain syndrome; 1 from multiple sclerosis, and; 1 from paraneoplastic syndrome.

Methods

Institutional review board approval was obtained for the original grounded theory study and again for the secondary analysis of the original data. All participants signed consent forms in the original study. One-on-one interviews were carried out by the first author in a designed conference room in the College of Nursing on the university campus. Neighborhood sites (e.g. libraries) that were safe and accessible were also used. Participants were interviewed once and encouraged to tell their stories about growing up with a parent who suffered with CNCP. A funnel approach to asking questions was used, (i.e., open-ended questions were asked first, followed by more specific questions guided by emerging data according to grounded theory principles). Each audio-recorded interview lasted 60 to 90 minutes and was followed by a short period of debriefing. Clinical and demographic data were collected at the end of the interview. Each participant received \$35 compensation. Participants' behaviors during the interview, along with reflections about the environmental and emotional context

of the interview, were recorded in field notes after completion of the interview.

Data Analysis

Audio-taped interview data were transcribed, verified, and stored in digital (NVivo) and hard copy form. All personal identifying information was deleted from the transcripts. The first author listened to the interviews after each was transcribed and made additional notes and summaries. During the secondary analysis, data were first analyzed by the two authors individually. Each transcript was examined in depth. On the basis of the research questions, all relevant sections of each transcript were highlighted and separated, forming a subtext; transcripts of all 30 interviews provided rich subtext for the secondary analysis. Next, short codes that captured the essence of each of the participant's comments in the subtext were composed by each author.

Several lengthy analysis meetings were held to organize and group codes into categories that shared similar characteristics. Codes were grouped together based on each author's "tacit and intuitive senses," using a process of negotiated consensus as described by Saldana (2013). Three cycles of code categorization were performed by the authors, during which time rearrangement and re-categorization of codes occurred. Iterative, narrative memos were written throughout the analysis to develop and track coding and category decisions. The following five categories that reflected ways participants experienced resilience and growth as a result of living with parental CNCP emerged from the data: (a) expanded ways of thinking; (b) cultivated a strong character; (c) aided in the development of skills; (d) instilled a commitment to live well, and; (e) nurtured spiritual growth. A content-analytic table was used to display the codes that contributed to each category. The contents of each category were described to give an understanding of the subtext. Exemplary quotes from the transcripts were assigned to each category (Miles, Huberman, & Saldana, 2014). In order to understand whether male and female participants' perceptions of resilience and growth were alike or different, numbers of male and female participants reporting each category were compiled (Table 1).

Rigor was established according to accepted standards of qualitative research. The research team approach provided investigator triangulation, as did prolonged engagement with the data and frequent investigator debriefing. Further rigor was enhanced by the use of comprehensive data analyses memos to record decisions about determining, naming, and coding categories. Credibility was strengthened by using participant's actual words in the description of each category.

RESULTS

Five areas of resilience and growth emerged from the data. The first was a heightened or expanded way of thinking about and understanding the world. Next was the development of qualities that led participants to believe that their characters were stronger as a result of growing up with parents who had CNCP. A commitment to live well and the ability to acquire and hone specific skills were other areas of growth. Finally, living with parental CNCP as children and adolescents helped to nurture their spirituality.

Expanded Ways of Understanding

A common theme that emerged from the data was growth in participants' abilities "to look beneath the surface" as they thought about experiences in their lives and grasped the complexities of seemingly straightforward situations. For many participants, they lived as children and adolescents with parents who were disabled by pain, yet looked healthy on the outside, who exhibited perplexing changing moods, and who lacked the ability or energy to communicate about what was happening and its effects on family members. Growing up, participants were compelled to make sense of these realities.

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