

Special Article - Family Caregivers

Military Spouses Caring for a Child with Autism: Exploring Risk and Protective Factors

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Received: January 21, 2016; **Accepted:** February 10, 2016; **Published:** February 12, 2016

Abstract

Caring for a child with a diagnosis of autism spectrum disorder (ASD) in the context of a military lifestyle is a task that more than 20,000 United States military spouses face today. Despite this prevalence, there is limited research that considers the complex set of challenges that these caregivers endure, and the process by which they strive to adapt to such challenges. The goal of this study was to identify aspects of everyday life that serve to facilitate and/or inhibit the resilience process for military caregivers of children with ASD. A series of semi-structured interviews were conducted with 18 spouses of active duty military personnel who have a child with ASD, ages 4 to 12 years old. These personnel comprised four branches of the United States Uniformed Services, including: Army (n=13), Marine (n=2), Navy (n=2), and Air Force (n=1). Families were stationed at installations across the country, representing bases in 9 states and in the District of Columbia. An iterative process of thematic analysis was conducted, which yielded six theme categories including aspects of risk (*barriers/stressors*), as well as protective factors (*supports/resources*, and *strategies*). Findings from this study may inform programs and policies that aim to support caregiver resilience and subsequent family wellbeing.

Keywords: Caregiving; Autism; Military families; Resilience; Family routines

Introduction

More than 23,000 United States military dependents, the majority of them children, have a diagnosed autism spectrum disorder (ASD) [1]. These families face a daunting set of challenges in everyday life in the presence of both the demands of living a military lifestyle as well as raising a child with ASD. Such circumstances place these caregivers in the crux of an ongoing resilience process. Military families with children with ASD are confronted with fluctuating legislation that drives eligibility for necessary educational and medical services [2].

The terms 'risk' and 'protective' are used in the literature to describe factors that serve to support or inhibit the resilience process for military families [3-6]. Evidence suggests a link between protective factors and a family's ability to successfully respond to challenges [6]. Therefore, exploring the lived experiences of these caregivers is vital to understanding the factors that impact resilience processes. By identifying those circumstances that leave families vulnerable, as well as ways in which caregivers might be empowered, supports could be put into place to optimize caregiver and family wellbeing. This study aims to explore mechanisms that serve to facilitate and/or inhibit the resilience process for military spouses caring for a child with ASD using qualitative methodology.

Resilience

Through a theoretical framework of family stress and coping, *resilience* models provide a means for understanding the ways in which individuals and families respond to challenges [7-9]. *Resilience* is considered to be a process by which adverse circumstances is effectively managed [10], whereas *resiliency* is a measurable outcome or indicator of such a process [11]. Conceptual frameworks of resilience have been valuable in understanding stress and coping in

military personnel and their families [12,13] as well as in caregivers of children with ASD [14,15]. Although predisposing risks impact outcomes, researchers have concluded that *protective factors* greatly impact an individual or group's ability to overcome hardships [16,17]. For this reason, the current study describes caregiver experiences to include risk, but aims to highlight the supportive components of resilience processes.

Military families

Military service has been described as a way of life that requires both personal and family sacrifice in support of the broader military mission [18]. Active duty military families face such ongoing challenges as frequent geographic mobility, family separations and risk of injury or death [19]. Military spouses are at risk for experiencing such distressing symptoms as anxiety and depression [20] and are at an increased risk for mental health diagnoses surrounding times of their service member's deployment [21]. During this time, spouses are faced with increased burden surrounding caregiving and household duties [22]. These demands often result in feelings of loneliness, financial concerns, and increased parenting demands for spouses [23]. Further, spouses must contend with the challenges of shifting roles and the reintegration of their returning family member into everyday life following deployments [24-27].

These challenges are compounded considerably by the demands of caring for a child with ASD. The Department of Defense [28] and National Council on Disability (2011) have identified such problematic circumstances for these families as a lack of portability of eligibility and service allotment across duty stations and subsequently suggest a critical need for systemic changes in both policy and practice for Exceptional Family Member (EFMP) families. A recent study by

Davis & Finke [29] also explored the experiences of military families with children with ASD and found that relocation and separation leads to stress and anxiety for the child as well as creating challenges for the non-military caregiver.

ASD and caregiving

Autism is a neuro developmental disorder with core deficits in social-communication and repetitive behaviors [30]. Caring for a child with ASD can be incredibly challenging. There is a wealth of evidence highlighting poor health outcomes for caregivers of ASD as related to their child's overall symptom severity and challenging behaviors [31-36]. In addition, a child's lack of social reciprocity and difficulty with emotion regulation significantly contribute to feelings of caregiving stress [37,38]. Caregivers have also reported stress surrounding the elusive nature of the disorder, to include professional's inability to identify and explain ASD [36]. Further, caregivers have identified concerns surrounding their child's future, identifying effective treatments, and difficulty understanding their child's needs [39].

Current study

Caregivers with a child with an ASD diagnosis face daunting challenges that may be compounded by the stress of military life in a combat era. Despite the prevalence of this population and the multiple risk factors that may constrain resiliency outcomes, little is known about the mechanisms that facilitate the resilience process for military families with a child with ASD. Understanding mechanisms of resilience for caregivers who face chronic stressful circumstances may yield an increased understanding of individual and family level outcomes such as wellbeing, particularly for families who may be considered at risk [40]. This study aimed to identify factors that inhibit or strengthen opportunities for responding to challenges that may serve to impact caregiver resiliency.

Participants

Participants included 18 active duty military spouses who were each the primary caregiver to their child with ASD between 4 to 12 years of age. While all participants were female, this was not a specific inclusion criterion. Families represented four branches of the Uniformed Services, including: Army (n=13), Marine (n=2), Navy (n=2), and Air Force (n=1) and included both Officers (n=13) and Enlisted (n=5) personnel. At the time of interviews, families were stationed at various installations across the country, representing bases in nine different states (North Carolina, Virginia, Florida, Georgia, Kentucky, Colorado, Pennsylvania, California, and Hawaii) and in the District of Columbia. Fourteen of the families had multiple children, with four of those having more than one child with ASD.

Methods

This qualitative study used a sequence of three in-depth semi-structured interviews that facilitated the data collection process. Open-ended interview questions covered topics targeting family experiences of raising a child with ASD in the context of a military life-style. These questions were formulated based on a review of the literature surrounding such theoretical concepts as resilience and family wellbeing [9,41]. The first interview explained study procedures, consent, and gathered basic demographic information. The second interview included open-ended questions targeting aspects

of resilience such as perceived stressors, family supports, as well as interpretations surrounding resiliency. In-depth questions were then generated to facilitate a third interview, which yielded a more in depth dialogue to follow-up and expand on the data generated from the second interview. The first and third interviews were conducted over the phone, and in some cases using SKYPE. Second interviews were conducted face-to-face when possible, usually in the participant's home, and otherwise over the phone. All participants consented to study procedures by signing an Institutional Review Board approved consent form prior to beginning in the interview process.

Data analysis

A recursive process of thematic analysis occurred throughout data collection, analysis, and writing phases of this study using Atlas.ti software [42]. Thematic analysis included six phases, 1) becoming familiar with the data, 2) line-by-line coding, 3) merging codes 4) identifying themes, 5) naming theme categories and 6) relating themes back to initial research questions [43]. Following the analysis process, data were then integrated into a comprehensive descriptive model in order to generate conclusions, connect findings to the existing literature, as well as integrate multiple concepts and findings [2].

The first step of analysis involved becoming familiar with the data through a verbatim transcription of the interviews and field notes. The second step involved line-by-line coding to generate initial emergent codes that identified common ideas at the most basic and descriptive level using a constant comparison method [44]. A second round of coding combined groups of codes that represented comparable ideas. Themes were then identified by conceptually grouping coded data into meaningful categories that were both internally consistent as well as distinct from other themes [45]. Six theme categories were identified. Next, theme categories were named to communicate a meaningful summary of the represented data [46]. Finally, themes were tied back to the initial research questions and discussed within the context of existing literature.

Results

Findings revealed six theme categories, three of which related directly to risk and resiliency and are thus discussed in this paper, to include *barriers* and *stressors*, *resources* and *supports*, and caregiver *strategies*. Similar to previous research, the concepts of risk and *protective factors* are used to categorize those components that serve to inhibit (*risk*) or support (*protective*) the broader process of resilience.

Risk factors - *barriers* and *stressors*

Throughout the interviews, caregivers described situations and experiences that they perceived as challenging. These *barriers* and *stressors* included circumstances that arose causing caregivers to experience distress surrounding their ability to effectively meet the needs of their family. *Barriers* and *stressors* were categorized into six themes including 1) complex systems, 2) life on base, 3) geographic relocation, 4) community outings, 5) isolation, 6) deployments, and 7) meeting the needs of other children.

Caregivers engaged in an ongoing process of navigating complex systems to meet the needs of their child with ASD. These systems were portrayed as disjointed, particularly from one duty station to the

next, and were at the mercy of ever changing policies which impacted eligibility and service quality. Several caregivers described their role of navigating and coordinating services for their child as a “full time job”. One mother labeled the process of obtaining services for her child as “completely overwhelming”, particularly following a new diagnosis of ASD.

Caregivers additionally faced challenges surrounding living on base, including a lack of available supports as well as barriers to obtaining housing that met the needs of their child with ASD. Caregivers revealed that while most bases provided family support or morale programs, these programs were rarely appropriate for their family based on the specific needs or abilities of their child. Mothers also portrayed challenges surrounding obtaining adequate housing on base to meet the safety needs of their child with ASD. Several families subsequently chose to live off base so that they could make modifications to their home, such as putting up a fence to ensure their child’s safety.

Caregivers faced incredible challenges surrounding geographic relocations while, on average, moving every three to five years. In addition to the challenging logistics of up-rooting a family, these moves resulted in a lack of consistency of healthcare providers, a lack of portability of Individual Education Plans (IEP’s) from state to state, and lengthy gaps in service allocation. These relocations often left caregivers feeling isolated and constrained in their ability to effectively meet the needs of their child.

Barriers were also described in terms of challenging aspects of participation in outings in the community. Caregivers faced barriers to participation in terms of their child’s challenging behaviors, most often in the context of eating out in restaurants, going to movies, or running everyday errands. Grocery shopping was consistently identified as problematic, particularly during times of separation or deployment. In addition to managing their child’s behaviors in the store, mothers reported the added challenge of having to find specialty grocery stores to meet the dietary needs of their child.

Caregivers expressed feelings of isolation associated with having a child with ASD. These feelings often stemmed from limited opportunities to form connections with other families due to the needs of their child with ASD. Mothers identified feelings of stress surrounding an ongoing need for explanation and apology surrounding their child’s problematic behaviors. In addition to feeling a lack of support, this feeling of isolation appeared to pose a threat to the caregiver’s successful integration into the military community.

Deployments were consistently described as challenging and compounded the aforementioned barriers and stressors. During times of deployment, caregivers served as a primary support to their deployed service member while simultaneously managing all of the needs of the family on the home front. Caregivers often felt like a “single mom” during these cycles of deployment. In addition, mothers identified challenges in facilitating the process of reintegration of their service member into family life following deployments.

Finally, caregivers faced challenges in meeting the needs of their other children, or those without an ASD diagnosis. Since family life was often centered on the needs of the child with ASD, caregivers felt that their other children were forced to make sacrifices, particularly in

terms of extra-curricular activities or quality family time. One mother described how her 10-year-old ‘typical’ son had never participated on a sports team because of the constraints of daily therapy sessions. Another mother cried as she explained how her dreams of teaching her ‘typical’ daughter to speak her native language, travel, and go to museums was on hold because of the intensity of caregiving that her son with ASD required.

Protective factors - resources & supports

Caregivers attempted to cope with significant challenges which involved an ongoing process of enacting available resources and supports. Quality resources and supports played a vital role in supporting the process of resilience, and included both ASD-related services as well as those that served to support the caregiver and family. These resources and supports primarily consisted of social supports and online networks, ASD-specific resources, and military and community programs.

The importance of building a community of social supports and online networks that transcended geographic location was highly endorsed by all participants in the study. The common link between these social connections appeared to be the caregiver’s desire for a shared understanding of experience, a sense of acceptance, and opportunities to mentor other caregivers. These communities often consisted of other ASD moms and/or military spouses, neighbors, family members and friends from back home, and/or mothers who shared common caregiver-related interests such as homeschooling. Online supports were particularly important to many caregivers due to the transient nature of a military lifestyle. Online groups such as American Military Families Autism Support (AMFAS) and other ASD-related blogs (e.g., Autism Speaks) or *Facebook* (e.g., base-specific EFMP group) allowed caregivers to navigate resources as well as feeling a sense of community across geographic location. The AMFAS group in particular was often endorsed as a valuable online tool to get information and support for military families with a child with ASD, particular during times of planning for relocation.

ASD-specific resources were also vital in supporting family resilience. Caregivers formed team of specialists, to include developmental pediatricians as well as teachers and other therapists (e.g., OT, PT, SLP) that played a vital role in meeting the needs of their child. Caregivers overwhelmingly emphasized the importance of Applied Behavior Analysis (ABA) as a necessary therapeutic intervention that supported their child’s goals as well as the caregiver in facilitating strategies that could incorporate their child’s needs and abilities into everyday family life.

Other military and community programs served as important resources for caregivers and their families. These included recreation-related organizations such as on-base Morale, Welfare and Recreation (MWR) programs and Family Readiness Groups (FRG), the local YMCA, as well as respite care programs. Caregivers had varying levels of participation in these groups and organizations, often times based on the needs of their child with ASD. For example, caregivers identified family support events on base such as movie or bowling nights that they were not able to attend due to their child’s sensory issues. These missed opportunities for community building were particularly isolating for families during their spouse’s deployments. Caregivers, therefore, often found that such community organizations

as the YMCA and Boy Scouts of America better fit the needs of their family. Overall, these organizations provided opportunities for families to participate in activities together while simultaneously offering an atmosphere of understanding, empathy and acceptance.

Protective factors - strategies

In addition to having access to quality resources and supports, caregivers endorsed the use of various *strategies* to ameliorate burdens in their everyday lives. These strategies included both coping skills as well as the use of tools to facilitate ease of everyday life, usually specific to their child's needs. Strategies included advocacy efforts, taking respite time, creating systems of organization and managing family routines, and cognitive approaches to coping.

Caregivers in this study advocated tirelessly for their child with ASD. The role of advocate took many forms, from making sure that the basic needs of their child were being met (for example navigating service systems) to lobbying on Capitol Hill targeting insurance policies that negatively impacted EFMP families. In addition, caregivers identified their role as a mentor to younger families, or caregivers whose child had recently been diagnosed. Other mothers portrayed advocacy efforts in terms of the time they spend educating themselves about their child's needs and the therapies that would positively impact their lives. Several caregivers reported feeling like advocacy and caregiving went hand in hand. To optimally meet the needs of their child, they educated themselves, spent time case managing their child's doctor's appointments and therapies, as well as provided support and mentorship to other caregivers. In this sense, advocacy appeared to ignite a type of job-related stress while simultaneously providing an outlet for some caregivers. One mother found more comfort in doing research about ASD on the computer and communicating with other caregivers online than having free time to engage in activities not related to ASD. Many caregivers served in their communities in various capacities as volunteers or educators for various organizations (e.g., national ASD organizations, hospital and state education boards, etc.). Overall, caregivers described their advocacy efforts as both necessary to meet the needs of their child as well as personally meaningful. Additionally, advocacy often facilitated participation in communities, which facilitated caregiver's participation in building support systems.

Several caregivers emphasized the importance of respite, as some of them called "me time". While most caregivers did not have consistent opportunities for respite, especially during deployments, all caregivers expressed the importance of having time to themselves. Some caregivers utilized respite hours allotted through their child's insurance while others called on neighbors and family members for support. "Me time" was labeled as "rejuvenating" and "essential" and was often spent running errands or grocery shopping, exercising, participating in hobbies such as crafts, or in a few cases going to work. One mother whose husband was deployed and who did not have respite hours reported counting on the one hour a day that her son had in-home therapy so that she could take a shower. Most caregivers similarly reported a lack of services in regards to respite care and relied heavily on their spouses for support when they were not deployed.

Creating systems of organization and consistent family routines were highly endorsed as effective strategies by most caregivers.

Organizational tools facilitated the caregiver's ability to case manage their child's services as well as supported the maintenance of everyday routines. Organizational tools consisted of record keeping systems that caregivers developed to maintain information related to child healthcare, education and therapeutic records. These tools eased the burden of a lack of a centralized record keeping system for health care documentation across duty stations. Additionally, organizational tools such as calendars, white boards and visual charts were used to in the home to facilitate consistent daily routines. Family routines served to meet the needs of the child with ASD, but also the broader family by providing a sense of stability, particularly during times of transition.

Caregivers revealed cognitive approaches to coping, which were utilized to regulate emotions during distressful situations or were embedded as a consistent habit within the context of everyday life. When describing their use of cognitive approaches to coping, the words "hope" and "survive" emerged. Caregivers hopeful about their child's future when they could put their faith in something outside of themselves, such as God or even a particular therapy or intervention. Additionally, caregivers adjusted their expectations in order to feel more optimistic about their child's future. Overall, cognitive strategies facilitated tolerating feelings of being overwhelmed in specific situations as well as provided a means for feeling encouraged and hopeful.

Discussion

Mothers of children with ASD who simultaneously fulfill the roles of caregiver and military spouse face incredible challenges. These caregivers respond by enacting resources that primarily aim to meet the needs of their child as well as various coping strategies that aim to overcome distressful moments or to find hope in the face of chronic stressors. Below, these findings are discussed in the context of the literature, with a focus on caregiver strategies. In order to frame this discussion, a typology set forth by Folkman & Lazarus [47] is used to categorize coping into two types, to include 1) task-focused and 2) emotion-focused strategies. Task-focused strategies aim to actively engage the caregiver in a task that will overcome or ameliorate the perceived barrier or stressor [47]. Emotion-focused strategies aim to regulate motions and are primarily cognitive in nature [48].

Task-focused coping strategies

Task-focused strategies were highly endorsed by participants in this study. Actively participating in the coping process through goal-oriented action was a common theme throughout all of the participant's experiences. Caregivers actively engaged in the resilience process by building communities of support, serving as an advocate for their child and the broader ASD or military community members, as well as using tools to manage everyday life.

Communities of support

These findings are consistent with previous literature that highlights the positive impact of social support on wellbeing for caregivers of ASD [49,50] as well as military spouses [51]. Similarly, research has identified the benefits of finding support from other parents of children with a disability through formal [52,53] and informal means of support [49,54]. Additionally, previous research emphasizes the importance of having a perceived *sense of community*

as contributing to positive outcomes such as wellbeing for military families [55,56]. This study extends these findings by highlighting the means by which caregivers build communities of support that transcend geographic location and a desire for shared experiences with other caregivers who understood their journey.

Advocacy

Findings also discovered that advocacy was a central component of caregiving. Literature has previously identified advocacy efforts as a component of caring for a child with ASD, particularly in the realm of early intervention and education [57,58], however this aspect of the caregiving role has been identified as largely unrecognized [59]. These findings extend this literature by highlighting the ways in which parent advocacy, a role that these caregivers inherently take on to meet the needs of their child, simultaneously provides caregivers with a sense of purpose and a connection to their communities of support. Further, an overlap appears to exist in the rank structure of both military spouse and caregivers of a child with ASD in that the duration of time 'in' (both military life and following a diagnosis with ASD), impacts the caregivers capacity to advocate for and support not only their own child, but also those caregivers who are lower-ranking or newer to the diagnosis based on their accumulated experiences.

Family routines

Caregivers structured daily routines to meet the needs of their child with ASD as well as to provide stability during times of transition (e.g., deployments). Findings are congruent with literature that places maintenance of everyday family routines as central to caregiver experience [60,61] and identifies that caregivers with children with ASD are tasked with restructuring daily routines based on the specific needs of their child [62,63]. Findings are further supported by previous literature that identifies the potential protective nature of family routines during times of stress [64], particularly for military families [6]. These findings extend the literature by suggesting that routines serve as a means by which military spouses/caregivers provide a predictable environment to meet the needs of family members (to include a child with ASD) on the home-front while simultaneously creating opportunities for the service member to participate in family life during times of separation or deployment.

Emotion-focused coping strategies

Caregivers used cognitive coping strategies to tolerate distressful moments and to find hope amidst their challenging circumstances. These findings align with previous literature that has identified emotion-focused coping strategies to be positively impacting military spouses [65] as well as caregivers of children with ASD [66]. Specifically, literature has found that caregivers of children with ASD utilize such strategies as cognitive reframing [67] and maintaining hope surrounding challenging circumstances [68]. Research also suggests that coping strategies may become increasingly cognitive in nature over time [69]. Findings from the current study extend current knowledge by delineating the use of various strategies in moments of distress (e.g., positive self-talk) versus those that were implemented on an ongoing basis (e.g., prayer).

Overall, findings from this study delineate the various resources and strategies that caregivers utilize in responding to challenging circumstances. These findings align with previous literature that has uncovered risk and protective factors for families with a child with

ASD as well as military families. Findings from this study extend the literature by highlighting the need for communities of support that are specific to caregiving for a child with ASD to foster a sense of belonging and knowledge sharing. In addition, this study highlights protective factors previously overlooked in the literature to include advocacy efforts and family routines as opportunities to meet both the needs of caregivers and their children with ASD. These findings suggest that while a number of strategies are used to respond to challenging circumstances, those that are task-oriented in nature were particularly salient as noted by their universal endorsement in this study. A study by Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter [70] similarly found that higher levels of problem-focused coping were associated with improved maternal well-being, even when controlling for ASD symptom severity. Thus, resiliency may be beneficially impacted in situations where caregivers are empowered to actively respond to challenges.

Conclusion

In conclusion, results from this study describe experiences of caring for a child with ASD in the context of a military lifestyle as they relate to the process of resilience. These findings highlight the importance of supporting caregiver's abilities to effectively respond to barriers and stressors. These challenges include gaining access to quality resources that meet the unique needs of their families as well as strengthening communities of support and promoting advocacy efforts. A general conclusion that can be drawn from these findings is that responding to stressors and challenges was an ongoing process by which caregivers strived to enact available resources and implementing various strategies, given their circumstances. Previous literature surrounding stress and coping for caregivers with a child with ASD similarly found that while caregivers strived to respond to demands, success was ultimately described as "doing the best as they could", by which Gray [71] succinctly concluded "Under the circumstances of autism, that is a considerable achievement" (p.299). Future studies may consider family level outcomes to include experiences of the service member as well as the transactional nature of mechanisms of change in the process of resilience. Also, future studies should consider family routines as a context for caregivers to participate in task-oriented coping strategies.

Acknowledgement

We are incredibly appreciative of the families who participated and made this study possible. We would also like to thank the following individuals for their support, guidance and expertise throughout this endeavor: Drs. Gary Bowen, Virginia Dickie, Ruth Humphry, and Linda Watson. This study was partially supported by NICHD3-R01-HD04216.

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