

## The experiences of adult children caring for a parent with Korsakoff's syndrome

Jessica L. Auslander<sup>1\*</sup>, Nancy A. Piotrowski<sup>2</sup>

### Abstract

**Background:** Korsakoff's syndrome (KS) is a debilitating psychoneurological disorder that can occur in adults with alcohol use disorder (AUD). People with KS experience a sudden onset of symptoms including confabulation, anterograde and retrograde amnesias, apathy, issues with vision and gait, and lack of insight. Frequently an adult child of the parent with alcohol-induced KS becomes the caregiver, regardless of the status or quality of the relationship with their parent. While there is a rich literature base in the areas of adult children of parents with AUD and caregiving, there are no studies that have explored the experiences of adult children caring for a parent with alcohol-induced KS. This study aimed to explore the experiences of adult children who provide care for a parent or parental figure suffering from alcohol-induced Korsakoff syndrome (KS).

**Methods:** This study used a generic qualitative approach with thematic analysis using both in person and web-based video interview methods and field notes to address this gap in the literature. Eight individuals participated in the study, men (n=2) and women (n=6), with participants ranging in age from 31 to 43 years (average age 37 years).

**Results:** Five themes emerged: addiction and the adult child, experiencing caregiver burden, experiencing a variety of emotions, professional healthcare experiences, and observations of symptoms. These themes emerged over seven anchor events in their caregiving experiences: interactions with their parent pre-diagnosis, parent's medical emergency, hospitalization, diagnosis, housing, legal, and financial.

**Conclusion:** The results provide a foundation for future research in the areas of KS, caregiving, and adult children of parents with AUD. They also provide a basis to inform the development of interventions with this population and demonstrate a need for more awareness of KS among healthcare professionals.

**Keywords:** Generic Qualitative, Korsakoff's Syndrome, Adult Child, Caregiver, Alcohol Use Disorder, United States

**Correspondence:** Jessica Levy Auslander (Jessica@pwmnc.com)

<sup>1</sup>Professional Wellness Management, Weddington, North Carolina, United States

**How to cite:** Auslander J, Piotrowski N. The experiences of adult children caring for a parent with Korsakoff's syndrome. *Journal of Ideas in Health*. 2024 August 31;7(4):1114-1122  
<https://doi.org/10.47108/jidhealth.vol7.iss4.356>

**Article Info: (Original Research)**

**Received:** 09 July 2024

**Revised:** 07 August 2024

**Accepted:** 16 August 2024

**Published:** 31 August 2024

© The Author(s). **2024 Open Access** This article is distributed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

The Creative Commons Public Domain Dedication waiver (<https://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article unless otherwise stated.

**Journal Home page:** <https://www.jidhealth.com>

**e ISSN:** 2645-9248

### Background

Korsakoff's syndrome (KS) is a permanent psychoneurological syndrome caused by thiamine depletion, most commonly as a result of alcohol use disorder (AUD) [1]. It is often discussed in combination with Wernicke's encephalopathy (WE) as Wernicke-Korsakoff syndrome (WKS). Wernicke's encephalopathy is the initial acute stage of brain swelling; if thiamine is quickly restored, recovery is possible [2]. If left unrecognized and untreated it can be fatal or result in KS [1]. Symptoms of KS include anterograde and retrograde amnesia, confabulation, apathy, social impairment, nystagmus, and impaired gait. It has a sudden onset, typically between the ages of 45-60. As most cases are misdiagnosed, there is some debate if it is always preceded by an episode of Wernicke's encephalopathy [3,4]. Those diagnosed with KS are usually unable to live independently but may not be aware of or have insight regarding their condition. Therefore, they may be confused and resistant when the adult child takes responsibility for aspects of their life such as housing, healthcare, finances, and legal matters as their informal caregiver. Caregivers are at risk for lower measures of various aspects of physical health, mental health, and overall wellbeing [5-9]. Wood and Tirone [10] suggested there may be additional challenges for those caring for someone with an addiction-related disorder such as confusing caregiving with enabling, experiencing consequences from the care recipient when trying to engage in self-care, and increased social isolation due to stigma and the care recipient's specific

behaviors. Family members of a person with an addiction-related disorder reported that there is little to no access to specialized services to support them as most treatment programs only offer resources within the context of treating the family member with addiction. These family members also report more physical ailments and prescription medication use [11]. Those caring for a family member affected by a mental health or addiction-related diagnosis reported higher levels of stress, fatigue, anxiety, depression, isolation, and resentment [12]. Hodges and Copello [13] noted that adult children caring for an adult with problem drinking behaviors experienced significant interpersonal conflict with the care recipient. It remains to be explored if this would be true of adult children who care for a parent with alcohol-induced KS. A study of adults diagnosed with KS in the Netherlands found that 26% of the participants were being cared for by an adult child [14]. Beyond the basic demographic information, no other information about KS caregivers has been collected; therefore, healthcare professionals generalize the needs of caregivers of other chronic illnesses (like dementia). While there may be similarities, this generalization has no foundation in the literature and does not take into account the unique and chaotic nature and dynamics of families affected by AUD. These families may experience further stigma and marginalization when seeking healthcare services [3]. The purpose of this study was to gain an understanding of the experience of adult children who care for a parent or parental figure with alcohol-induced KS.

## Methods

### Study design

This study was conducted using a generic qualitative methodology with thematic analysis as described by Percy et al. [15]. The generic approach was the most appropriate qualitative approach for this research study because it explores the content of the experiences of the participants as well as their thoughts and reflections on these experiences. This approach can be useful when conducting initial studies with populations that are underrepresented and is specifically indicated to expand the research base due to the wide range of needs and situations of adult children's caregivers [13,16].

### Participant Selection and Recruitment

A purposeful, maximum variation, saturation sampling was used. Inclusion criteria: age 18 years or over; caring for a parent or parental

figure who has alcohol-induced KS, and living in the United States. Potential participants who may have experienced extreme distress or exacerbation of untreated symptoms of mental health disorders when discussing caring for their parent were excluded. Recruitment was through advertising in a Facebook group for those affected by KS, a Facebook group dedicated to adult children of parents with AUD, and on the Family Caregiver Alliance's graduate research registry. The recruitment protocol was amended in response to the COVID-19 event and stay-at-home orders. The sample was composed of eight adults; six of the participants were female, two were male, and the ages ranged from 31-43 (average age was 37 years). The demographics of the participants are presented in Table 1.

### Data Collection and Analysis

All interviews were conducted by the principal investigator. The first five interviews were conducted in-person in public locations that offered private space to protect confidentiality in a location that was convenient to the participant. Due to the COVID-19 pandemic and subsequent orders to stay home, the remaining interviews were conducted online through a secure web-based video portal. A series of open-ended questions were asked to guide participants in describing their experiences caring for their parent with KS. Field notes were taken to record any significant behaviors of the participants. The interviews lasted approximately one hour each, were recorded with a digital audio recorder and transcribed into Microsoft Word. The field notes were summarized for each participant and included with each transcribed interview. QSR NVivo 12 was used to assist in the analysis. The data were analyzed through the process of inductive analysis as described by Percy et al. [15]. The data from each interview were analyzed individually to identify patterns. The patterns from each interview were then combined across all interviews and streamlined into the themes discussed below.

### Researcher-Designed Guiding Interview Questions

The following prompts were used in the interviews:

1. Please share with me what it was like to grow up in your home.
2. Please walk me through how your parent came to be diagnosed with Korsakoff's syndrome.
3. Please share with me how your life changed after your parent's diagnosis.
4. I am wondering, given your experiences with your parent, what have been the most challenging aspects of caregiving?

**Table 1:** Participant demographic information

Participant	Gender	Age (years)	Marital Status	Children	Highest Education Completed	SES	Parent
1	F	37	M	Y	High School	Middle	Father
2	F	43	P	Y	Doctorate	Middle	Mother
3	M	34	S	N	College, no degree	Middle	Father
4	F	35	M	Y	Masters	Upper	Mother
5	F	40	M	Y	Professional Degree	Middle	Mother
6	F	42	P	Y	Masters	Middle	Father
7	M	31	M	N	Bachelors	Middle	Father
8	F	37	M	Y	Doctorate	Upper	Mother

Note. SES = socioeconomic status. Marital Status: M = married, P = partnered, S = single. All participants identified as White, non-Hispanic, Latino, or Spanish.

## Results

This study yielded a substantial amount of rich data about the experiences of adult children caring for a parent with alcohol-induced KS. Five themes emerged from the data: addiction and the adult child, experiencing caregiver burden, experiencing a variety of emotions, professional healthcare experiences, and observations of symptoms. Across these themes, 23 psychological experiences were identified across seven anchor events. The full tables of meaning units and sub themes can be requested from the corresponding author.

### Theme 1: Addiction and the Adult Child

The participants shared stories and examples of their parent's addiction-related behavior; all but two of the participants described childhood memories affected by AUD. All participants described parentification (e.g. 'I'm her parent right now'; 'it's a weird process becoming the parent to your parent'). The participants described conflict with other family members related to their parent, confronting their parent about their AUD before the onset of KS, and expecting their parent to have another alcohol-related health issue, such as cirrhosis, cancer, or kidney failure. As they were not aware of KS before their parents' diagnoses, the participants did not anticipate having to care for memory or behavioral issues. The perception that addiction is a choice extended to behaviors related to KS and led some to question the nature of their relationship with their parent as an adult child. Participants discussed how the KS diagnosis further impacted their relationship ('it's learning how to have a relationship with a sober person that can't remember anything'). Participants who had distanced themselves from their parent due to their AUD suddenly became involved in their parents' lives after the KS diagnosis and experienced conflict when trying to navigate the dynamics of their relationship ('I've thought of her as a black hole for a long time, sort of like to get anywhere near is to get sucked into the darkness').

### Theme 2: Experiencing Caregiver Burden

Participants' descriptions of caregiver burden included feeling that they had no choice in becoming their parent's caregiver, feeling unsupported, going against their parent's wants, housing issues, questioning their efforts, self-sacrifice, and tasks. This theme illustrated both the psychological burden as well as the burden of completing time-consuming tasks to care for their parent. The participants who did not want to re-engage with their parent acknowledge that they legally had a choice, but they were not comfortable with their parent becoming a ward of the state, creating a moral or ethical conflict. Many described how their parent had alienated partners and other family members, leaving the participants to make decisions about their parent's healthcare, financial, housing, and legal matters on their own, often knowing that they were going against their parent's wants or plans for their life before the KS diagnosis. Two participants shared that they were representing their parent in their parent's divorce proceedings. Housing issues emerged as a significant concern for all participants. A person with KS cannot live independently, and with the sudden onset, there is little time to transition from independent living to assisted living or living with family. Only one participant found a placement for their parent that could adapt to the unique needs of a person with KS. Others shared

being denied by assisted living arrangements, or losing placements due to their parent's behavior or finances.

Participants questioned if their efforts on behalf of their parent were making a difference, often within the context of not fully understanding the diagnosis and treatment options. Participants expressed a desire to help their parent, but also a fear that if their parent recovered, they would resume drinking. All participants discussed sacrificing their energy, emotional wellbeing and resources to care for their parent. Issues such as balancing caring for their parent as well as their own partners and children were discussed, as well as the impact of crossing previously set boundaries for engagement with their parent.

### Theme 3: Experiencing a Variety of Emotions

A wide range of emotions was described by participants throughout the interviews. Of the 22 emotions uncovered in the interviews, 17 were presented as painful or unresolved for the participants. The complexity of the participants' emotional experiences impacted their relationships with their parent and other family members. The participants also demonstrated detachment and empty-chair processing during the interviews.

### Theme 4: Professional Healthcare Experiences

A significant part of the adult child caregivers' experiences was interacting with healthcare professionals. They shared the common experiences of their parent experiencing a healthcare crisis that involved the onset of KS, hospitalization, recommendation of supervised care, and managing follow-up care. When discussing their interactions with healthcare professionals, six subthemes emerged: the term *alcoholic dementia*, healthcare resources, lack of information, misdiagnosis, positive experiences, and stigma. Most of the participants struggled with finding professional support and guidance from physicians.

### Theme 5: Observations of Symptoms

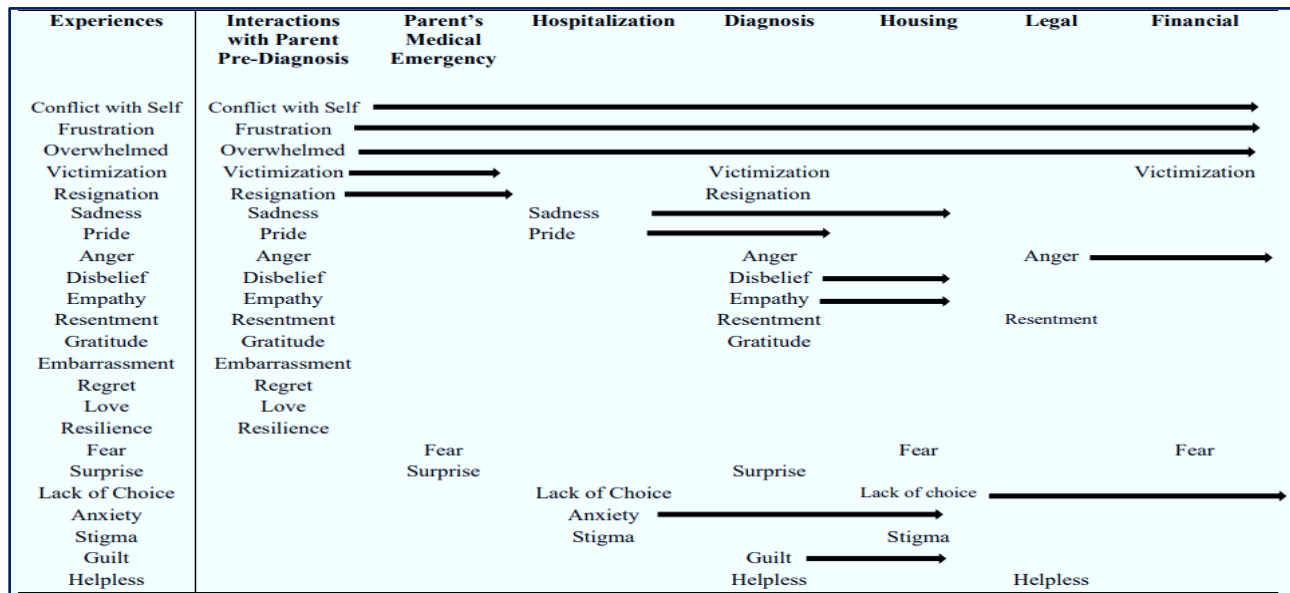
Participants discussed a variety of physical, emotional, and cognitive symptoms they saw in their parent with alcohol-induced KS. Most of them were observed during their parent's medical emergency or after diagnosis when the caregivers had more interaction with their parent. The caregivers identified 21 symptoms, with no prior knowledge of KS they could not determine which symptoms were indicative of the onset of KS and which were related to chronic alcohol use or co-occurring diagnoses.

### Experiences by Anchor Events

The participants described both the internal and external anchor experiences of caring for their parent with alcohol-induced KS. Figure 1 shows the psychological experiences described by the participants during each event in their care experience. The anchor events are listed in chronological order, and the psychological experiences are listed in the order they emerged during the anchor events. The next level of organization is by number of anchor points affected, then the impact on the caregiver (increasing in valence within each time point). Participants described their relationship with their parent before diagnosis and shared a wide variety of emotions. This event is referred to in Figure 1 as Interactions with Parent Pre-Diagnosis. The participants described a medical or psychiatric emergency

that led to at least one hospitalization and then diagnosis. Some participants described more than one hospitalization experience with their parent. After the parent was diagnosed, participants discussed the process of finding housing for their parent. The housing process was typically connected to the parent's discharge from the hospital, as they could not return to living independently, and due to the sudden onset of the illness, no prior arrangements had been made. The housing process often triggered involvement in their parents' legal and financial affairs. The experiences of the adult children caring for their parent with

KS can also be interpreted by the number of emotions expressed at each event. Participants shared the greatest number of emotions when discussing their interactions with their parent pre-diagnosis, followed closely by their discussion of their parent's diagnosis of KS. The next event was handling their parents' housing situations. Participants described fewer emotions when discussing their experiences with their parents' hospitalizations, and the same number of emotions when describing the events of the medical emergency, legal, and financial issues.



**Figure 1.** Psychological experiences by order of occurrence, number of anchor points affected, and impact on caregiver (negative to positive) across anchor events. In general, legal issues preceded financial, but this may vary by individual situation.

## Discussion

This study revealed seven caregiving anchor events and five themes that combined to make up the experiences of the adult child caring for a parent with alcohol-induced KS. The caregiving anchor events can loosely be chronological, keeping in mind that some may experience multiple hospitalizations and the caregivers may encounter the housing, legal, and financial issues at various times during their caregiving experiences. These events are a logical progression of what is involved caring for a parent with KS in the United States, and the themes further illustrate the degree of caregiver burden, both in emotional experiences and tasks. Regardless of age of onset of the parent's AUD, the adult child was affected by their parent's addiction-related behaviors. This led to a range of experiences, such as having to care for their parent, trying to minimize the severity of the impact of their behavior, confronting their parent, experiencing conflict with other family members, perceiving their parent's behaviors as a choice, and ultimately questioning their relationship with their parent. Existing literature demonstrated that parental AUD can have a profound effect on the child [17-20], but there is little to show how this relationship evolves as the child becomes an adult and takes on a caregiving role to their parent. The adult child re-engaged in their parent's care after the diagnosis of KS. Participants encountered healthcare professionals with little or no awareness or knowledge of the diagnosis. Many symptoms of WE and KS are similar to acute alcohol withdrawal [4, 21]; participants reported their parent was misdiagnosed and stigmatized.

Those with KS may also have complex medical needs but poor insight into their diagnoses and levels of functioning, requiring more support from both formal and informal caregivers [22]. There is a paucity of studies to inform professional or informal caregivers as to how to care for a person with KS, leaving individuals to navigate this difficult situation on their own [23]. Participants felt they had no choice in taking on a caregiving role and received little or no support from other family members. The adult child may be the only person willing to become a caregiver due to the negative impact of AUD on family and social relationships; this perceived lack of choice may lead to higher levels of stress [24-25]. Caregivers of those with addiction-related disorders often have a smaller social network, fewer resources to care for their family member, and less ability to prioritize their own self-care [26]. Participants described a variety of tasks that addressed their parent's housing, medical, legal, and financial needs; in performing these tasks they often had to make decisions that they felt their parents would not have wanted them to make. People with KS do not have insight into their abilities, so they think nothing is wrong. Therefore, they frequently resist changes with housing, financial matters, and legal status. Since communication skills are not affected, others may perceive the person as having full capacity, causing legal or ethical complications [27-28]. All participants shared that they did not have enough information or resources to make caregiving decisions, and described the various ways in which they sacrifice the needs of their own families and wellbeing to care for their parents. Participants recognized that it was normal to care for a



parent as they aged, but they did not expect to be caring for their parent in middle age, or when they were also juggling the demands of raising their own families. Caregivers shared a wide range of emotions and described several of their parents' symptoms. Caregivers of those affected by AUD could be at higher risk for significant levels of stress, depression, anxiety, resentment, and isolation [12-13]. Three experiences were consistent across all caregiving events and occurred with other emotions: conflict with self, frustration, and feeling overwhelmed. Anger was discussed pre-diagnosis, at diagnosis, and when discussing legal and financial issues. Participants described feeling like they did not have a choice during hospitalization and when managing housing, legal, and financial issues; these are the caregiving events that are task oriented. Therefore, caregivers experienced both the task-oriented and emotional aspects of caregiver burden as described by Pearlin et al. [29]. Participants expressed resentment pre-diagnosis, at diagnosis, and when discussing legal matters, consistent with experiences of adult children of parents with AUD [30]. It is logical that participants would express resentment during the events that are directly related to the parent's AUD when the adult child views the addiction as a choice, especially when those events resulted in the caregiver taking on personal legal matters such as divorce. The participants described experiencing stigma; it has been established that stigma can have a significantly negative impact on caregivers and is a common issue among those caring for someone with an addiction-related disorder [12, 31-32]. Lack of their own awareness contributed to experiencing surprise at the medical emergency and diagnosis, as many expressed that they were unaware of the diagnosis prior to their parent's experiences and that they expected other health issues instead. While most of the experiences and emotions discussed were presented as negative or painful, a few positive emotions were expressed. Participants expressed love for their parent and resilience during the pre-diagnosis event. Gratitude was also expressed pre-diagnosis and again during diagnosis; participants were grateful that their parent's situations were not life-threatening or more severe. Participants expressed pride pre-diagnosis, during hospitalization and diagnosis events. Participants were proud of their ability to advocate for their parent and proud of the rehabilitative progress their parent made after receiving care. The positive aspects of caregiving should not be overlooked by future researchers on this topic, as it could inform strengths-based interventions for clinicians.

### Implications

This study added knowledge to the areas of adult children of parents with AUD, KS, and caregiving. The findings of this study elaborated on the knowledge of the multigenerational impact of alcohol use disorder. If the parent develops KS, it could potentially re-engage the adult child who may have intentionally distanced themselves. The parent's AUD is now affecting both the adult child and the adult child's own family and children [33]. There is a lack of consensus in the current literature regarding specific diagnostic criteria for KS [3]. One common statement is that KS is the result of untreated episodes of WE caused by chronic alcohol use. In this study the participants shared a variety of timelines of their parent's alcohol use; while six participants discussed memories of their parents drinking excessively since their childhood, two participants stated their parents had only

developed AUD a few years before their KS diagnosis. Participants also described a wide range of symptoms they observed at the time of their parent's medical emergency and diagnosis; this information could further inform the conceptualization of the syndrome. The caregivers' descriptions of their parent's symptoms were consistent with the existing literature on KS. The generally accepted list of symptoms includes irregular eye movements, apathy, anterograde amnesia, retrograde amnesia, ataxia, confabulation, neuropathy, lack of insight and disorientation to time and place; onset may or may not occur after an episode of WE [3-4,34-36]. The participants described symptoms more commonly associated with acute alcohol withdrawal or post-acute withdrawal syndrome, indicating an opportunity for education and support as they care for their parent. The most confounding symptom for caregivers was the lack of insight of their parent, as this complicated facilitating healthcare, housing, and legal decisions. Caregivers often had to decide to go against their parent's expressed wishes in order to secure housing or make healthcare decisions, a phenomenon that van den Hooff and Goossensen [37] referred to as "imposing care" (p. 71).

### Healthcare Professionals

This study provided several insights that could be useful for healthcare providers and addiction professionals. The caregivers described relationships with their parents and other family members as being characterized by conflict and a wide range of complex emotions that included resentment, embarrassment, and victimization. As quality of relationship between caregiver and care recipient can be a protective factor against caregiver burden, it is likely that this population would be at a high risk for caregiver burden or other stress-related problems [38]. Those with AUD or KS may exhibit several mood symptoms or disruptive or embarrassing behaviors which may lead to significant symptoms of depression or burden in the caregiver [39-40]. Some with KS may have stopped drinking just prior to their diagnosis or as a result of their diagnosis. A supportive family is vital to coordinating the multidisciplinary team that is needed to support stabilization and partial recovery for those with KS, but in many cases the family members not prepared to engage as quickly as would benefit the person with KS [41]. Caregivers may become hopeful that they can reconnect with or repair their relationship with a sober parent; however, the cognitive and affective symptoms of Korsakoff's syndrome may prevent this, causing further distress to the adult child [42]. Like caregivers of dementia, caregivers of KS may experience pre-death grief and would benefit from professional support to process this experience [43]. Mental health professionals working with caregivers should be aware that issues related to being raised by a parent with AUD are further complicated by caring for a person with a sudden onset of KS and who may have co-occurring medical or psychiatric diagnoses. Each of these factors alone would be clinically significant [44-46]; this research shows the potential complexity of psychological experiences across caregiving events when these factors combine. Caregivers may present as detached and could benefit from a clinical interview style that is closer to information gathering at first than focusing on the individual's potential psychopathology [47]. The initial information gathering process could be therapeutic in a way that is less direct, but still revealing

about the caregiver's needs. The age of onset complicated the housing issue for many; their parents were not old enough for age-related financial benefits and most memory care assisted living facilities are designed for older residents. Korsakoff's syndrome by itself does not affect longevity. In a study of patients with alcohol-induced KS, half of the participants died within eight years of diagnosis, mostly due to cancer or serious bacterial infections [48]. Caregivers will need case management services to assist with longer-term financial planning for their parent as well as support to help them manage their parent's needs as well as the needs of their own young families. The findings highlight the need for increased awareness of KS. If an episode of WE is treated quickly it can prevent the onset of KS and provide an opportunity to educate the person and their family [4]. However, it is often mistaken for acute alcohol withdrawal or other diagnoses unrelated to addiction, and the opportunity for prevention is missed. It is often assumed that permanent brain damage is the result of years of chronic alcohol use; while some cognitive effects have been attributed to usage over time, the amnesic symptoms of Korsakoff's syndrome can occur acutely when alcohol is consumed while malnourished [49]. Even when diagnosed correctly and timely, caregivers are still unable to find accurate information, leaving them questioning if their efforts are making a difference or worth their time and sacrifice.

### Research

This study demonstrated the challenges with recruiting this population. There is no central organization dedicated to KS with a network of patients, researchers, and care providers, so recruitment for this study was done primarily through social media. While it has been an effective recruitment tool for many other psychological or medical studies, it presents privacy concerns and eliminates potential participants who are not on social media [50]. There is a demand among this population to be heard; the researchers received many inquiries from those did not qualify because they had a relationship other than adult child, their care recipient's KS was not due to alcohol, or they were not in the United States, presenting avenues for future studies. There is a need for further research to build from this data to create future qualitative, quantitative, or mixed-methods studies; first qualitative to uncover new conceptualizations about addiction-related phenomenon, then quantitative to study the relationships among them [51].

### Limitations

Korsakoff's syndrome is often misdiagnosed or underdiagnosed [3,52], and there is currently no professional association or foundation in the United States dedicated to education, treatment or research. Recruitment was primarily from a social media group dedicated to Wernicke-Korsakoff syndrome. While social media has been demonstrated to be an effective recruiting tool to access rare populations, it also has its limitations, such as privacy concerns [50, 53]. It is likely that there are other adult children caring for a parent with alcohol-induced Korsakoff's syndrome who are not active on social media or in the group and who are not connected with the Family Caregiver Alliance. It is also possible that many in this population were hesitant to come forward due to fear of or prior negative or stigmatizing experiences. Even as adults, children of parents affected by alcohol use disorder may not easily disclose information about

their family due to a need to maintain balance and a perception of normalcy [54]. While generalization is not the goal of a qualitative study, it is worth noting that the sample did not include anyone reporting lower socioeconomic status or a race or ethnicity other than Caucasian, non-Hispanic, Latino, or Spanish. Therefore, it is not known if those with a lower SES or different racial or ethnic backgrounds have different caregiving experiences. Also, while two of the participants were males, they were both caring for their fathers, so the mother-son dynamic was not represented in this study. This study focused on the experiences of those currently caring for a living parent with alcohol-induced KS, so another limitation is that topics related to end of life were not discussed. Due to the COVID-19 pandemic, the last three interviews were completed over a secure web-based portal instead of in-person. While video-based online interviews have become accepted for use in qualitative research, in-person interviews are still preferred due to the role of non-verbal cues in communication, possible ethical issues surrounding technology use and confidentiality, and the ability to create rapport between the researcher and participant [55]. It is possible that using a web portal could have affected the level of personal disclosure of the participants, creating a difference between those interviewed in person and those interviewed online [56].

### Recommendations for Further Research

Any of the events or themes could be explored in more depth or with a different methodology. The participants in this study discussed other family members; therefore, more could be done to explore the adult child's relationships with other family members, including the impact on the caregivers' children. Another research opportunity could address other caregiver-care recipient relationships, such as siblings or partners to those with KS as they would likely have a different perspective. There may be a difference in subjective caregiver burden between spousal caregivers and adult children [57-58]. Another avenue to explore could be adult children of those with KS who did not choose to take on the caregiving role. This study focused on those living in the United States (and participants were either in the Midwest or South), so further research could be done on caregivers in other geographic areas, as resources and laws that impact caregivers vary by state and country. This study also demonstrated that more work is needed to explore the legal implications of autonomy in those with impaired cognitive functioning, specifically those who confabulate. This study could only go as far as the experiences of the participants. While one participant reported that her parent had been diagnosed approximately seven years before the interview the other participants reported the time between diagnosis and interview to range from 3-24 months. More research is needed to explore how the caregivers' experiences progress through time or how they experience caregiving if their parent stabilizes medically and behaviorally. Another avenue to explore could be caregivers who have experienced the death of their care recipient, as they could provide a different perspective on their experiences as well as information about caring for someone with KS at the end of life.

### Conclusion

Adult children of a parent with AUD may suddenly re-engage with their parent as their caregiver after the parent is diagnosed with KS. This qualitative study is the first to explore these

experiences. The themes of addiction and the adult child, experiencing caregiver burden, experiencing a variety of emotions, professional healthcare experiences, and observations of symptoms emerged over seven anchor events in their caregiving experiences: interactions with their parent pre-diagnosis, parent's medical emergency, hospitalization, diagnosis, housing, legal, and financial. This data provides a foundation for future research for this underrepresented population.

#### Abbreviation

ACE: African Center of Excellence, BTd: Biosensors Technology Development, IRPM: Innovative Rodent Pest Management, CDC: Center for Disease Control, CNS: Central Nervous System, EMJH: Ellinghausen-McCullough-Johnson-Harris culture medium, IPM: Institute of Pest Management, MAT: microscopic agglutination test;  $\mu$ m: microliter; NBS: National Bureau of Statistics; OCGS: Office of Chief Government Statistician; OIE/WOAH: World Organization for Animal Health; RPM: revolutions per minute, SUA: Sokoine University of Agriculture; WHO: World Health Organization; ZALIRI: Zanzibar Livestock Research Institute; ZFDA: Zanzibar Food and Drug Authority.

#### Declaration

The authors declared that this article is part of the previously published "dissertation" titled "Adult Children Caring for a Parent with Korsakoff's Syndrome: A Qualitative Study," which is available in the "Capella University ProQuest Dissertations & Theses (2020, ID: 28260534)". You can access it via the following link:  
<https://www.proquest.com/openview/e03191186cc1f855f955048763f5d873/1?pq-origsite=gscholar&cbl=18750&diss=y>.

#### Acknowledgment

None.

#### Funding

The authors received no financial support for the research, authorship, and publication of this article.

#### Availability of data and materials

Data will be available by emailing Jessica@PWMNC.com

#### Authors' contributions

This article is based on the dissertation completed by Jessica Levy Auslander-JLA (2020). The principal investigator (JLA) completed the interviews and analysis. The co-investigator Nancy A. Piotrowski (NAP) served as the dissertation mentor, reviewing all data analysis and assisted with writing and revising the article. Both authors read and approved the final manuscript.

#### Ethics approval and consent to participate

We conducted the research following the declaration of Helsinki. The ethical approval was obtained from the Institutional Review Board of Capella University. Informed consent was obtained from the participants before interviews were conducted.

#### Consent for publication

Not applicable

#### Competing interest

The authors declare that they have no competing interests.

#### Author Details

<sup>1</sup>Professional Wellness Management, Weddington, North Carolina, United States

<sup>2</sup>Behavioral Health Sciences, University of California, Berkeley Extension, California, United States

#### References

1. Donnelly A. Wernicke-Korsakoff syndrome: recognition and treatment. *Nurs Stand*. 2017 Mar 29;31(31):46-53. <https://doi.org/10.7748/ns.2017.e10440> PMID: 28351256.
2. Sinha S, Kataria A, Kolla BP, Thusius N., Loukianova LL. Wernicke encephalopathy: clinical pearls. *Mayo Clin Proc*. 2019 Jun;94(6):1065-1072. <https://doi.org/10.1016/j.mayocp.2019.02.018>.
3. Arts NJM, Walvoort SJW, Kessels RPC. Korsakoff's syndrome: a critical review. *Neuropsychiatr Dis Treat*. 2017;13:2875-2890. <https://doi.org/10.2147/NDT.S130078>.
4. Thomson AD, Guerrini I, Marshall EJ. The evolution and treatment of Korsakoff's syndrome. *Neuropsychol Rev*. 2012;22, 81-92. <https://doi.org/10.1007/s11065-012-9196-z>.
5. Fonareva I, Oken BS. Physiological and functional consequences of caregiving for relatives with dementia. *International Psychogeriatrics*. 2014;26(5):725-47. <https://doi.org/10.1017/S1041610214000039>
6. Gonzalez EW, Polansky M, Lippa CF, Walker D, Feng D. Family caregivers at risk: who are they? *Issues Ment Health Nurs*. 2011;32(8):528-36. <https://doi.org/10.3109/01612840.2011.573123>.
7. Kim,Y, Schulz, R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 2008;20(5), 483-503. <https://doi.org/10.1177/0898264308317533>.
8. Kim H, Chang M, Rose K., Kim S. Predictors of caregiver burden in individuals with dementia. *Journal of Advanced Nursing*. 2011;68(4), 846-855. <https://doi.org/10.1111/j.1365-2648.2011.05787.x>.
9. Pot AM, Deeg DJH, Van Dyk R. Psychological well-being of informal caregivers of elderly people with dementia: changes over time *Aging & Mental Health*. 1997;1:3, 261-268, DOI: 10.1080/13607869757164.
10. Wood S, Tirone S. The leisure of women caring for people harmfully involved with alcohol, drugs, and gambling. *Journal of Leisure Research*. 2013;45:5, 583-601, <https://doi.org/10.18666/jlr-2013-v45-i5-4364>
11. Orford J, Velleman R, Copello A, Templeton L, Ibanga A. The experiences of affected family members: a summary of two decades of qualitative research. *Drugs: Education, Prevention and Policy*. 2010;17:sup1, 44-62, <https://doi.org/10.3109/09687637.2010.514192>
12. Slaunwhite AK, Ronis ST, Sun Y, Peters PA. The emotional health and well-being of Canadians who care for persons with mental health or addictions problems. *Health and Social Care in the Community*. 2017;25(3), 840-847. <https://doi.org/10.1111/hsc.12366>.
13. Hodges M, Copello A. "How do I tell my children about what my mum's like?" conflict dilemma in experiences of adult family members caring for a problem-drinking parent.

- Families, Relationships, and Societies. 2015;4(1), 87-101. <https://doi.org/10.1332/204674314S13951456077308>.
14. Gerritzen IJ, Goossensen MA. Patients with Korsakoff syndrome in nursing home: characteristics, comorbidity, and use of psychotropic drugs. *International Psychogeriatrics*. 2014;26(1):115-21. <https://doi.org/10.1017/S1041610213001543>.
  15. Percy WH, Kostere K, Kostere S. Generic qualitative research in psychology. *The Qualitative Report*. 2015; 20(2), 76-85. <https://doi.org/10.46743/2160-3715/2015.2097>
  16. Cook SK, Snellings L, Cohen SA. Socioeconomic and demographic factors modify observed relationship between caregiving intensity and three dimensions of quality of life in informal adult caregivers. *Health Qual Life Outcomes*. 2018, 16(1), 169-180. <https://doi.org/10.1186/s12955-018-0996-6>.
  17. Alford KM. Family roles, alcoholism, and family dysfunction. *Journal of Mental Health Counseling*. 1998;20(30), 250-260. <https://search.proquest.com/openview/c4fbf6467addf194cbde411b577b7227/1?pq-origsite=gscholar&cbl=47399>.
  18. Cook L. Perceived conflict, sibling position, cut-off, and multigenerational transmission in the family of origin of chemically dependent persons: an application of bowen family systems theory. *Journal of Addictions Nursing*. 2007;18(3):p 131-140. <https://doi.org/10.1080/10884600701500495>
  19. Grant BF. Estimates of US children exposed to alcohol abuse and dependence in the family. *Am J Public Health*. 2000 Jan;90(1):112-5. doi: 10.2105/ajph.90.1.112. PMID: 10630147; PMCID: PMC1446111
  20. Hall CW, Webster RE. Multiple stressors and adjustment among adult children of alcoholics. *Addiction Research & Theory*. 2207; 15(4), 425-434. <https://doi.org/10.1080/16066350701261865>.
  21. Long L, Long B, Koyfman, A. The emergency medicine management of severe alcohol withdrawal. *Am Jour Emerg Med*. 2017;35(7), 1005-1011. <https://doi.org/10.1016/j.ajem.2017.02.002>.
  22. Van Dam MJ, van Meijel B, Postma A, Oudman E. Health problems and care needs in patients with Korsakoff's syndrome: a systematic review. *J Psych Mental Health Nursing*. 2020;27(4), 460-481. <https://doi.org/10.1111/jpm.12587>.
  23. Gerritzen IJ, Hertogh CM, Joling KJ, et al. Caregivers' perspectives on good care for nursing home residents with Korsakoff syndrome. *Nursing Ethics*. 2021;28(3):358-371. <https://doi.org/10.1177/0969733020921507>
  24. Li L, Lee Y. Caregiving choice and caregiver-receiver relation: effects on psychological well-being of family caregivers in Canada. *Canadian Journal on Aging / La Revue canadienne du vieillissement*. 2020;39(4):634-46. <https://doi.org/10.1017/S0714980819000825>
  25. Schulz R, Beach SR, Cook TB, Martire LM, Tomlinson JM, Monin JK. Predictors and consequences of perceived lack of choice in becoming an informal caregiver. *Aging in Mental Health*. 2012;16(6), 712-721 <https://doi.org/10.1080/13607863.2011.651439>
  26. Settley C. The physical and psychological wellbeing of caregivers in individuals suffering from substance addiction. *Archives of Psychiatric Nursing*. 2020;34(3). 107-109. <https://doi.org/10.1016/j.apnu.2020.03.007>
  27. van den Hooff S. Transcending responsibility: a way to justify beneficial coercion of patients suffering from Korsakoff's syndrome? In: Gather J, Henking T, Nossek A, Vollman J, editors. *Beneficial coercion in psychiatry: foundations and challenges*. Munster: Mentis; 2017. pp. 221-236. [https://doi.org/10.30965/9783957438157\\_016](https://doi.org/10.30965/9783957438157_016)
  28. Haalboom R, van Aken L, Walvoort SJW, Egger JIM, Kessels RPC. Preserved intellectual functioning in Korsakoff's syndrome? actual and premorbid intelligence in patients with major or mild alcohol-related cognitive disorder. *Journal of Substance Use*. 2019; 24(5), 532-538. <https://doi.org/10.1080/14659891.2019.1619101>
  29. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*. 1990; 30(5), 583-594. <https://doi.org/10.1093/geront/30.5.583>
  30. Haverfield MC, Theiss JA. A theme analysis of experiences reported by adult children of alcoholics in online support forums. *Journal of Family Studies*. 2014; 20(2), 166-183. <https://doi.org/10.1080/13229400.2014.11082004>
  31. Garg R, Gupta A, Kundal D. Comparison of impact of family stigma on quality of life among inpatients with alcohol and opioid use disorder. *Industrial Psychiatry Journal*. 2019; 28(2), 278-285. [https://doi.org/10.4103/ipj.ipj\\_83\\_19](https://doi.org/10.4103/ipj.ipj_83_19)
  32. Rafiq M, Sadiq R. Caregiver stress, perceived stigma and mental health in female family members of drug addicts: correlational study. *J Pak Med Assoc*. 2019 Sep;69(9):1300-1303. PMID: 31511715.
  33. Järvinen M, Bloch C. Sympathy and misery in families with drinking problems. *Acta Sociologica*. 2017; 60(1), 75-88. <https://doi.org/10.1177/0001699316652210>
  34. Bonnelle V, Manohar S, Behrens T, Husain M. Individual differences in premotor brain systems underlie behavioral apathy. *Cerebral Cortex*. 2016; 26(2), 817-819. <https://doi.org/10.1093/cercor/bhv247>
  35. El Haj M, Nandrino J-L. Feedback and repetition as a tool to rehabilitate time perception in Korsakoff's syndrome: a case study. *Journal of Systems and Integrative Neuroscience*. 2016; 3(1), 1-5. <https://doi.org/10.15761/JSIN.1000145>
  36. Wijnia JW, van de Wetering BJ, Zwart E, Nieuwenhuis KGA, Goossensen MA. Evolution of Wernicke-Korsakoff syndrome in self-neglecting alcoholics: preliminary results of relation with Wernicke-delinium and diabetes mellitus. *The American Journal on Addictions*. 2012; 21, 104-110. <https://doi.org/10.1111/j.1521-0391.2011.00199.x>.
  37. van den Hooff S, Goossensen A. Conflicting conceptions of autonomy: experiences of family carers with involuntary admissions of their relatives. *Ethics & Social Welfare*. 2015; 9(1), 64-81. <https://doi.org/10.1080/17496535.2014.937450>
  38. Tough H, Brinkhof MW, Siegrist J, Fekete C. Subjective caregiver burden and caregiver satisfaction: the role of partner relationship quality and reciprocity. *Archives of Physical Medicine and Rehabilitation*. 2017; 98(10), 2042-2051. <https://doi.org/10.1016/j.apmr.2017.02.009>
  39. Cheng S-T. Dementia caregiver burden: a research update and critical analysis. *Current Psychiatry Reports*. 2017; 19(64), 1-8. <https://doi.org/10.1007/s11920-017-0818-2>
  40. Gerritzen IJ, Moerman-van den Brink WG, Depla MF, Verschuur EML, Veenhuizen RB, van der Wouden JC, Hertogh CPM, Joling KJ. Prevalence and severity of behavioural symptoms in patients with Korsakoff syndrome and other alcohol-related cognitive disorders: a systematic review. *Int J Geriatr Psychiatry*. 2017;32: 256-273. PMID: 27918121 DOI: 10.1002/gps.4636



41. Oudman E, Oey MJ, Batjes D, van Dam M, van Dorp M, Postma A, Wijnia JW. Wernicke-Korsakoff syndrome diagnostics and rehabilitation in the post-acute phase. *Addiction Neuroscience*. 2022; 4. <https://doi.org/10.1016/j.addicn.2022.100043>
42. Drost R, Postma A, Oudman E. Cognitive and affective theory of mind in Korsakoff's syndrome. *Acta Neuropsychiatrica*. 2019; 31(3), 128-134. <https://doi.org/10.1017/nev.2018.35>.
43. Blandin K, Pepin R. Dementia grief: a theoretical model of a unique grief experience. *Dementia*. 2017; 16(1), 67-78. <https://doi.org/10.1177/1471301215581081>
44. Labrum T. Caregiving for relatives with psychiatric disorders vs. co-occurring psychiatric and substance use disorders. *Psychiatric Quarterly*. 2018; 89, 631-644. <https://doi.org/10.1007/s11126-017-9557-0>
45. Pereira HR, Botelho MAR. Sudden informal caregivers: the lived experiences of informal caregivers after an unexpected event. *Journal of Clinical Nursing*. 2011; 20(17), 2448-2457. <https://doi.org/10.1111/j.1365-2702.2010.03644.x>
46. Tyo MB, McCurry MK. An integrative review of measuring caregiver burden in substance use disorder. *Nursing Research*. 2020; 69(5), 391-398. <https://doi.org/10.1097/NNR.0000000000000442>
47. Rossetto KR. Qualitative research interviews: assessing the therapeutic value and challenges. *Journal of Social and Personal Relationships*. 2014;31(4), 482-489. <https://doi.org/10.1177/0265407514522892>
48. Sanvisens A, Zuluaga P, Fuster D, Rivas I, Tor J, Marcos M, Chamorro AJ, Muga R. Long-term mortality of patients with an alcohol-related Wernicke-Korsakoff syndrome. *Alcohol and Alcoholism*. 2017; 52(4), 466-471. <https://doi.org/10.1093/alcac/agx013>
49. Salmon DP, Butters N. The etiology and neuropathology of alcoholic Korsakoff's syndrome: some evidence for the role of the basal forebrain. In: Galanter M, editor. *New York: Springer. Recent developments in alcoholism (vol. 5); 1987. pp. 27-58* [https://doi.org/10.1007/978-1-4899-1684-6\\_2](https://doi.org/10.1007/978-1-4899-1684-6_2)
50. Sanchez C, Grzenda A, Varias A, Widge AS, Carpenter LL, McDonald WM, Nemeroff CB, Kalin NH, Martin G, Tohen M, Filippou-Frye M, Ramsey D, Linos E, Mangurian C, Rodriguez CI. Social media recruitment for mental health research: a systematic review. *Comprehensive Psychiatry*. 2020. <https://doi.org/10.1016/j.comppsy.2020.152197>
51. Järvinen M. Understanding addiction: adult children of alcoholics describing their parents' drinking problems. *Journal of Family Issues*. 2015; 36(6), 805-825. <https://doi.org/10.1177/0192513S13513027>
52. Isenberg-Grzeda E, Kutner HE, Nicolson SE. Wernicke-Korsakoff syndrome: under-recognized and under-treated. *Psychosomatics*. 2012; 53(6), 507-516. <https://doi.org/10.1016/j.psych.2012.04.008>
53. Burton-Chase AM, Parker WM, Hennig K, Sisson F, Buzzzone LL. The use of social media to recruit participants with rare conditions: Lynch syndrome as an example. *JMIR Research Protocols*. 2017; 6(1), e12. <https://doi.org/10.2196/resprot.6066>
54. Werner A, Malterud K. Children of parents with alcohol problems performing normality: a qualitative interview study about unmet needs for professional support. *International Journal of Qualitative Studies on Health and Well-being*. 2016; 11(1), 1-11. <https://doi.org/10.3402/qhw.v11.30673>
55. Iacono VL, Symonds P, Brown DHK. Skype as a tool for qualitative research interviews. *Sociological Research Online*. 2016; 21(2), 103-117. <https://doi.org/10.5153/sro.3952>
56. Ruppel EK, Gross C, Stoll A, Peck BS, Allen M, Kim S-Y. Reflecting on connecting: meta-analysis of differences between computer-mediated and face-to-face self-disclosure. *Journal of Computer-Mediated Communication*. 2017; 22(1), 18-34. <https://doi.org/10.1111/jcc4.12179>
57. Oldenkamp M, Hagedoorn M, Slaets J, Stolk R, Wittek R, Smidt N. Subjective burden among spousal and adult-child informal caregivers of older adults: results from a longitudinal cohort study. *BMC Geriatrics*. 2016; 16(208), 1-11. <https://doi.org/10.1186/s12877-016-0387-y>
58. Rigby T, Ashwill RT, Johnson DK, Galvin JE. Differences in the experiences in caregiving between spouse and adult child caregivers in dementia with Lewy bodies. *Innovation in Aging*. 2019; 3(3), 1-15. <https://doi.org/10.1093/geroni/igz027>