




Up-Close and Personal: Conceptualizing the Self as Dementia Caregiver: a Study in Soweto, South Africa

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Abstract

The aim of this study was to understand how dementia caregivers in the township of Soweto, South Africa interpret their role in the context of caregiving through the personal constructs identified using the *Self-Characterization* technique. Thirty family caregivers were recruited via purposive sampling methods and completed a Self-Characterization Sketch during semi-structured interviews. Content analysis of construct pairs was thematically coded using the Classification System for Personal Constructs (CSPC) - a reliable method to analyse personal constructs that are generated by constructivist assessments. Findings revealed that caregivers' interpretations of themselves was characterized by moral, emotional and cognitive attributes. Specifically, a sense of mastery, self-efficacy, strength, selflessness and unconditional positive regard characterized the most meaningful constructs of care within caregiver narratives in response to their loved ones with dementia. These adaptive outcomes, despite the challenging, pervasive, complex nature of dementia and its manifestations, suggest psychological and emotional resilience, higher levels of adjustment and caregiver well-being. However, it is important to consider possible consequences such as physical fatigue and burnout despite adaptive outcomes. Therefore, it is recommended that approaches to psychoeducational initiatives, emotional and psychological interventions and awareness campaigns include teaching caregivers how to self-care encourage the importance of consistent exercise, rest, sleep, nutrition as well as reaching out for social support. Lastly, empowering caregivers to use their personal resources would prove valuable in support groups, and individual to facilitate self-awareness, sustained coping and mental health.

Keywords Caregivers · Dementia · Meaning-making · Personal constructs · self-care · Well-being

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Introduction

The dementia caregiver experience – is a phenomenon extensively studied across the globe due to high prevalence and mortality rates. According to World Health Organization (WHO, 2021) estimates, there are 55.2 million individuals living with dementia globally and 1.9 million in Africa. Furthermore, global mortality rates in 2019 were estimated at 1.62 million (Global Burden of Disease; GBD, 2021). In low and middle-income (LMIC) countries such as Sub-Saharan Africa, prevalence rates are expected to increase by 70–90% (De Jager et al., 2015). This is a concern especially in LMIC, where healthcare services are grossly under resourced (Kalula & Petros, 2011). Subsequently, the myriad of stressors that are unexpectedly imposed upon family caregivers has been documented in the literature (Kabir et al., 2020; Ransmayr et al., 2018) and shown to alter the course of family caregivers' life trajectories (Kontrimiene et al., 2021). However, among the negative and distressing sequelae that dementia caregivers endure, there has been a rapidly growing body of literature that has documented the positive and meaningful aspects of caregiving that serve as protective factors and linked to caregiver well-being, resilience and sustained mental health (Ashrafizadeh et al., 2021; Dias et al., 2015; Hawken et al., 2018; Palacio et al., 2020; Zhang et al., 2020).

Furthermore, a plethora of dementia caregiving literature has linked findings to suggested or possible interventions to alleviate caregiver burden and enhance well-being (Hepburn et al., 2007; Lethin et al., 2016; Narayan et al., 2015; Nguyen, 2021; Oswald et al., 2003; Walter & Pinquart, 2020; Wiegelmann et al., 2021). Many interventions have been developed, yet the effectiveness of these interventions have largely been inconclusive (Tak et al., 2019) or only small-to-moderate effect sizes have been found to improve some areas of distress and facilitate knowledge. As posited in an updated meta-analysis by Walter and Pinquart (2020), there is a need for interventions to be tailored to specific outcomes and that educational programmes are insufficient as a standalone intervention. Instead, these researchers suggest a combination of training and psychoeducation would prove more efficacious (Walter & Pinquart, 2020). However, it is crucial that the perceived needs of caregivers themselves should be prioritized to facilitate congruence between interventions and caregiver needs that are tailored as closely as possible within specific contexts as they arise (McCabe et al., 2016). To meet this objective, it is imperative to explore the lived experiences of dementia caregivers comprehensively and in collaboration with caregivers to avoid fulfilling prescriptive, or researcher-led interests (Caputi et al., 2012). This qualitative study employed a narrative approach using character sketches to encourage meaning-making on a deeper level using the principles of Personal Construct Theory (PCT; Kelly, 1955, 1991).

South African studies, albeit lacking have documented the lack of service provision, resource constraints, high levels of caregiver burden, and the need to intervene with both caregivers and diagnosed family members for improved functioning (Bosch, 2014; Gurayah, 2015; Hendriks-Lalla & Pretorius, 2018; Mahomed & Pretorius, 2020; Pretorius et al., 2009; Van der Poel & Pretorius,

Table 1 Inclusion criteria for the study

1. Caregivers should have already received a diagnosis of dementia for their loved one
 2. Caregivers should be a family member of the person with dementia
 3. In addition to the above, caregivers should reside in the same home in Soweto as their family member diagnosed with dementia
 4. Participants should be primarily responsible for activities of daily living for their loved one such as bathing, feeding, dressing, toileting and medication management
 5. Family caregivers should be taking care of their loved one for at least one year
 6. Caregivers should be comfortable conversing in English
 7. Caregivers should be 18 years or older
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2009). Furthermore, townships such as Soweto in South Africa have endured restricted water and electricity provision, basic sanitation, and a lack of infrastructure such as roads, schools, and healthcare facilities (Moolla et al., 2011). Challenges identified by primary healthcare users at health care facilities include long waiting times, inadequate service provision, and the lack of medical treatment (Gwabeni, 2016; Mabitsela, 2012; Morontse, 2010). These difficulties specific to a township may induce distinct experiences of dementia caregivers in South African townships. Hence, this is the first South African study to explore how Black African caregivers interpret their role in the context of dementia caregiving under challenging circumstances in the resource-constrained township of Soweto.

Methods

Sample and Recruitment

This study forms part of a larger study that explored the lived experiences of dementia family caregivers in a Black African township (Mahomed & Pretorius, 2021). Ethical clearance was granted for this study by the Research Ethics Committee at Stellenbosch University (PSY-2019-10582). Researchers of this study collaborated with *Alzheimer's South Africa*, (henceforth referred to as *Alzheimer's SA*) - a Non-Governmental Organization (NGO) actively involved in the psychoeducation of caregivers with the aim of facilitating a better understanding of the disease as well as ensuring the provision of improved care responses. This association also provides support groups for caregivers as a supportive resource (Kalula & Petros, 2011). Purposive sampling techniques were used to identify thirty family caregivers who met the inclusion criteria for the study as outlined in Table 1. These criteria was shared with the *Alzheimer's SA* Soweto office coordinator, who established initial contact with suitable participants to introduce the research objectives and explain the interview process. This was meant to allay any fears or hesitance associated with the study.

Caregivers who were interested to participate in the research were contacted telephonically by the first author to invite them to participate in the research. During this process, caregivers were informed that their choice to participate in the research was voluntary and to clarify that there will be no costs to them. Participants were reimbursed for the travel costs that were incurred for transportation to the *Alzheimer's SA Soweto* office.

After receiving verbal consent, face-to-face¹ interviews were scheduled at the *Alzheimer's SA Soweto* office to suit caregivers' schedules. Written consent was obtained before data collection commenced. To ensure confidentiality and the protection of the participants' identities, code names, for example 'Family Caregiver 1' (FC1), was used instead of using any real identifying data and any identifying information was omitted. Participant characteristics are outlined in Table 2 and a summary thereof in Table 3.

Overall, 70% of the sample consisted of female caregivers and 30% male, with a mean age of 48.7 years. Almost half the sample were daughters taking care of their mothers. Similarly, almost half of the sample had a tertiary level of education. In terms of persons with dementia, 20% were male and 80% female – majority of which were mothers being taken care of by their adult children.

Theoretical Framework

This study utilized George Kelly's Personal Construct Theory (PCT; Kelly, 1955) as a theoretical framework to guide the exploration of family caregiver experiences for their loved ones with dementia. The core assumption of PCT is that individuals construct the meaning of their own lives by creating personal theories, known as *construct systems* (Caputi et al., 2012). These construct systems, known to underpin Kelly's (1955) concept of *constructive alternativism* represent infinite constructions of reality that individuals may produce. A construct is defined as "a particular way individuals have of viewing, giving meaning to, or construing the individuals and events in their life and the world around them" (Kelly, 1955 as cited in Caputi et al., 2012, p. 4). When individuals construe or make meaning of their realities, they form personal constructs such as their own verbal language, phrases and expressions and use these constructs to assimilate these realities – thus underpinning the "abstracted, flexible and content-free" (Hamad, 2017, p. 31) philosophy of PCT. Due to this philosophy, PCT is an appropriate orientation for a multitude of real world phenomena including the construction of the realities of formal (Clinton et al., 1995) and informal caregiving (Wills & Woods, 1997) and intervention for individuals with dementia (Hamad, 2017).

Since the individual is the expert on their own unique process (Caputi et al., 2012), Kelly (1955) suggests finding ways to distil these processes. *Constructivist assessments* are used to "identify and explore personal narratives and constructions of the individuals experience, and evaluate his or her unique construct

¹ Data collection occurred during 2019, before the emergence of the Covid-19 pandemic.

Table 2 Sample characteristics (n = 30)

FC	Gender	Age	Dementia individual's relationship to caregiver	Caregiving dyad	Duration of caregiving (years)	HLOE
1	Female	30	Paternal Grandmother	Granddaughter caring for Grandmother	3	Tertiary
2	Female	50	Mother	Daughter caring for Mother	1	Tertiary
3	Male	28	Mother	Son caring for Mother	1	Matric
4	Male	58	Wife	Husband caring for Wife	5	Grade 7
5	Female	23	Mother	Daughter caring for Mother	2	Tertiary
6	Female	54	Mother	Daughter caring for Mother	5	Grade 11
7	Female	39	Mother	Daughter caring for Mother	6	Tertiary
8	Female	41	Mother	Daughter caring for Mother	3	Tertiary
9	Female	47	Mother	Daughter caring for Mother	2	Tertiary
10	Female	58	Mother	Daughter caring for Mother	2	Grade 10
11	Female	66	Husband	Wife caring for Husband	3	Tertiary
12	Male	47	Mother	Son caring for Mother	2	Matric
13	Female	20	Grandmother	Granddaughter caring for Grandmother	2	Matric
14	Male	22	Grandmother	Grandson caring for Grandmother	2	Matric
15	Female	51	Mother	Daughter caring for Mother	3	Tertiary
16	Male	30	Mother	Son caring for Mother	6	Matric
17	Female	52	Mother	Daughter caring for Mother	5	Matric
18	Male	51	Mother	Son caring for Mother	5	Grade 11
19	Female	74	Husband	Wife caring for Husband	4	Tertiary
20	Female	40	Mother	Daughter caring for Mother	1	Grade 10
21	Female	49	Mother	Daughter caring for Mother	2	Grade 11
22	Male	74	Wife	Husband caring for wife	2	Tertiary
23	Female	54	Mother	Daughter caring for Mother	4	Tertiary
24	Female	60	Sister	Sister caring for Sibling	3	Tertiary
25	Female	72	Husband	Wife caring for Husband	1.5	Grade 9
26	Female	50	Mother	Daughter caring for Mother	5	Matric
27	Male	54	Father	Son caring for Father	4	Grade 11
28	Female	63	Husband	Wife caring for Husband	1	Grade 10
29	Male	40	Mother	Son caring for Mother	1	Matric
30	Female	64	Husband	Wife caring for Husband	3	Tertiary

FC=Family Caregiver; HLOE=Highest level of education; Grade=level at school; Matric=refers to graduating from high school in South Africa; Tertiary=refers to college education

systems...” (Caputi et al., 2012, p. 5). Although there are multiple constructivist assessments (Neimeyer & Bridges, 2003), there are five seminal techniques that have been used to evaluate individuals’ construct systems (Caputi et al., 2012; Hamad, 2017). The first of these five techniques are - the *Repertory Grid*, which assesses how individuals view others and events in their social world via

Table 3 Summary characteristics of sample

Sample	Characteristics	Percentage (%) or mean average	
Dementia Caregivers	Age	48.7	
	Male	30%	
	Female	70%	
	Relationship category	Granddaughter	2
		Grandson	1
		Daughter	13
		Son	6
		Wife	5
		Husband	2
		Sister	1
		Education	Primary School
	High School	8	
	Matric	8	
Tertiary	13		
Persons with Dementia	Male	20%	
	Female	80%	
	Relationship Category	Grandmother	3
		Mother	18
		Wife	2
		Husband	5
		Father	1
		Sister	1

structured interview (Fransella et al., 2004; Kelly, 1955). Second, the *Implication Grid*, which is used to assess the correlation between constructs (Hinkle, 1965; Winter, 1992). Third, *Laddering*, which assesses core values (Hinkle, 1965; Neimeyer et al., 2001). The fourth technique is called the *Resistance to Change Grid*, which is designed to elicit core commitments or impasses (Hinkle, 1965; Winter, 1992) and the last technique is called *Self-Characterization*, which are narrative sketches written by the individual to explore self-constructs (Kelly, 1955; Winter, 1992). Understanding the experience of dementia caregivers through PCT allows the expansion of knowledge by examining the personal construct systems of dementia caregivers and “how it can be validated or reconstructed in the target population” (Hamad, 2017, p. 38). For the purpose of this study, the *Self-Characterization* technique was used to explore constructs that family caregivers identify in the context of their role as dementia caregivers.

Data Collection

The *Self-Characterization* sketch was the primary technique used for this component of the study. Kelly (1955) developed the *Self-Characterization* technique as a qualitative measure to identify self-constructions of the individual. It is designed in the form of a character sketch written in the third person, where the individual is asked to take a broader, in-depth view of him/herself instead of focusing on the sole interests of the researcher (Caputi et al., 2012).

As some authors have pointed out, there is a purposeful omission of a specific protocol or outline for the creation of a character sketch (Caputi et al., 2012; Winter, 1992). Designing a specific method to obtain a character sketch would result in “a considerable loss of spontaneity and a failure to discover the individual’s own conceptualization about himself or herself” (Caputi et al., 2012, p. 37). Furthermore, Kelly (1955) emphasized that the purpose of this flexible and exploratory technique is to ascertain how the individual construes his/her world in relation to a particular role that he/she embodies (e.g. dementia caregiver).

Kelly’s (1955) instruction was adapted to suit the study population as follows:

“On this paper, please write a description of (insert participant name), who is taking care of someone in their family with dementia. Think about (insert participant name) as if he/she was an actor on TV. Write it as if you are a friend who knows him/her very well and understands his/her feelings, better than anyone else. Be sure to write it in the third person. For example, you can start by saying, (insert participant name)...

If you prefer to say it to me, you can tell me and I will write it down as you speak.”

Twenty-two participants completed this exercise as a written task, whilst the remaining eight participants opted to verbally narrate their story to the researcher. The latter appeared to be more as a preference for these participants, as only one caregiver was unable to complete the task by writing due to poor literacy skills. After participants completed this exercise, they were asked to read their sketch and underline the words that were most meaningful to them (Caputi et al., 2012). For the narrated pieces, the researcher read the participants’ sketches back to the participants and they were asked to indicate to the researcher which words to underline. This produced the self-identified personal constructs of participants. Thereafter, participants were asked to describe the meaning underlying each identified construct. Once this process was completed, participants were asked to identify a word opposite to the first construct, thereby generating a dichotomous pair of constructs (Caputi et al., 2012). Lastly, each participant was asked to elaborate on the meaning of the opposite construct that they identified. Apart from the above-mentioned instructions, no further prompting was offered to ensure that all responses were purely the result of participants’ interpretations.

Consent was obtained from participants to audio record their responses to allow for verbatim transcription. Due to time restrictions, transcription was done by a professional transcribing service to ensure objectivity and accuracy of participants’ narratives.

Data Analysis

Content analysis of construct pairs was conducted using the Classification System for Personal Constructs (CSPC; Feixas et al., 2002). This was done to bring structure to copious narrative data that cannot be scored – a limitation of the *Self-Characterization* technique that Kelly (1991) himself identified (Caputi et al., 2012). The CSPC was designed as a reliable method to analyse personal constructs that are generated by constructivist assessments (Neimeyer, 1993; Feixas et al., 2002). According to the CSPC, there are eight categories that data can be thematically coded and applied to clinical populations and specific areas of study (Feixas et al., 2002). Table 4 outlines all CSPC categories briefly with examples as classified in Feixas et al. (2002).

Ensuring Trustworthiness

This study employed four methods to ensure trustworthiness: credibility, transferability, dependability and confirmability (Guba, 1981). Furthermore, peer debriefing, peer examination and member checks were used to ensure that the data was depicted fairly and truthfully (Long & Johnson, 2000). Similarly, the processes of reflexivity and triangulation were used to ensure that the study reflected the participants' perceptions to control for researcher bias and beliefs (Table 5).

Results

Content analysis revealed core constructs (indicated in bold where possible) that were identified through participants' character sketches. Our findings yielded four themes namely, 1). *The Moral Caregiver*; 2). *The Altruistic Caregiver*; 3). *The Emotionally Resilient Caregiver* and 4). *The Cognitive Aspects of Caregiving*. A comprehensive overview of participant constructs that were elicited through self-characterization sketches, the corresponding CSPC category to which it was assigned, and selected quotes to illustrate the meanings of shared constructs are included as [supplementary material](#).

Theme 1: The Moral Caregiver

This theme depicts the identified, shared constructs as moral characteristics (consistent with the Moral category of the CSPC) reflective of twenty-two caregivers, and their meanings thereof, which were highly subjective. The first subtheme presents the *Care* or *Taking care* constructs first, followed by the various dichotomous constructs and their meanings that were elicited to ensure coherence. These constructs are *Ignorant*; *Negligent*; *Irresponsible*; *Unkind*; *No Empathy*.

Table 4 A brief outline and description of CSPC categories with examples

CSPC Category	Description	Examples
Moral	Judgements made about an individual's character traits such as kindness, generosity, fairness and other characteristics as appropriate	Good – Bad Altruist – Egoist Humble – proud Respectful – Judgmental
Emotional	Descriptions regarding the degree of emotionality or sexuality and/or emotional attitude towards life	Visceral – Rational Warm – Cold Optimist – Pessimist Balanced – Unbalanced
Relational	Descriptions of all aspects of concerning relationships	Extroverted – Introverted Pleasant – Unpleasant Direct – Devious Tolerant – Authoritarian
Personal	Descriptions of characteristics related to personality, character that excludes traits regarded as moral, relational or emotional	Active – Passive Hardworking – Lazy Organized – Disorganized Decisive – Indecisive
Intellectual / Operational	Descriptions of skills, abilities and knowledge at intellectual and operational levels	Capable – Incapable Intelligent – Dull Cultured – Uncultured Focused – Unfocused
Values and Interests	Descriptions of ideological, religious or specific values and interests	Conservative – Liberal Traditional – Progressive Spendthrift – Thrifty Likes sports – Does not like sports
Existential	Descriptions of central appraisals such as issues of purpose, meaning or direction	Purposeful – Purposeless Growth – Stagnation Fulfillment – Emptiness
Concrete	Descriptions of concrete as opposed to abstract features or positions of people and their actions	Attractive – Ugly Rich – Poor Talks quickly – Talks Slowly Has lots of time – Has little time

CSPC = Classification System for Personal Constructs

Taking Care The most common construct identified as meaningful to caregivers was “care” or “taking care” within their narratives. To these caregivers, caring held various meanings such as “to look after somebody in a very good manner” (Q1)², to ensure that their loved one is in a “good space”, which means creating an environment suited to meet all their loved one’s needs (Q2). Furthermore, daily grooming, feeding and household tasks are meant to be done for your loved one with dementia as you would engage in them for “yourself” - “whole-heartedly” (Q3). In addition, for some caregivers taking care meant “to love someone” (Q4), “looking out for each other” (Q5), “making sure they are fine...listen[ing] to them...just to be there for them” (Q6). For other caregivers, to care meant having the ability to “think

² Quote numbers 1 to 76 correspond to comprehensive participant quotes provided as [supplemental material](#).

properly...to separate right from wrong and...to solve problems” (Q7). It also meant “accept[ance]” (Q8), “responsibility...loyalty [and] faithfulness” (Q9).

Ignorant; Negligent; Irresponsible; Unkind; No Empathy Conversely, caregivers identified constructs that reflected the dichotomous or opposite meaning of what “care” or “taking care” meant for them. Common constructs opposite to taking care included “ignorant”, meaning that “the person won’t bother, if the person sees things happening, the person won’t like need information about something to understand things better” (Q10), he “doesn’t want to know” (Q11). Furthermore, a person who does not take care was considered “negligent” or “neglectful” which meant that they lack a sense of “control”, “love”, “understanding”, “tolerance” (Q12) and that they are “cruel” (Q13) and always “angry” due to their lack of understanding (Q14). In addition, some caregivers considered a person who doesn’t “take care” as “irresponsible”, which meant that “they [don’t] care about the people around them” or “their environment” and are self-centred (Q15- Q17). Similarly, other caregivers characterised “someone who does not care” as “unkind” (Q18) and lacking “empathy” (Q19) to describe a person who is aloof within their surroundings.

Several other, but less common dichotomous constructs that caregivers identified included *Good versus Bad*; *Responsible versus Unresponsible*; *Hygiene versus Dirty* and *Clean versus Negligence*.

Good Versus Bad One caregiver appeared to evaluate the manner in which she cared for her mom as “good” (Q20) as evidenced by the meaning of her dichotomous construct. This participant described the abusive conditions under which an elderly person in her neighbourhood is living as the meaning of a bad” caregiver (Q21).

Responsible Versus Unresponsible Another participant made sense of her caregiver role meaning that she has become “responsible” enough to not only take care of her grandmother with dementia, but to help family and others who need support as well, describing herself as “wiser” (Q22). In contrast, she would be “unresponsible” if she did not help out at home and socialized like she used to before her grandmother became ill (Q23).

Hygiene Versus Dirty and Clean Versus Negligence Moreover, several caregivers identified constructs related to “hygiene” and “clean[liness]” with dichotomous constructs such as “dirty” and “negligence.” For these caregivers, keeping clean meant “dirt-free and fresh”, and implied good quality of care, whereas a person or home that is not clean would “show negligence” and would be considered “uncared for” and “untrustworthy” (Q24-Q26).

Theme 2: The Altruistic Caregiver

This theme depicts the altruistic traits that seventeen caregivers identified as constructs as they narrated their world as a caregiver through the lens of a third-person. This theme was most suited to the Moral category of the CSPC. Dichotomous pairs identified were *Sacrifice versus Selfish*; *Good listener versus Doesn’t listen*;

Table 5 Process of ensuring trustworthiness

Process	Sub-process	Description of steps taken
Credibility	Peer Debriefing	The data was verified with colleagues on an ongoing basis to consider additional and alternative perspectives for the duration of the entire interview process (Long & Johnson, 2000). The interviews, themes, and interpretations thereof were discussed between authors throughout the process.
	Peer Examination	The research proposal for the study was submitted to the Departmental Ethics Screening Committee and Research Ethics Committee: Human Research (Humanities) at Stellenbosch University prior to commencement of the study.
	Member Checks	Participants were given the opportunity to confirm the content of interviews during the interview process. The aim of this was to establish an accurate and clear understanding of the experiences of the participants.
Transferability		Contextual information is provided about the research context, processes and participants to allow for inferences regarding the transferability of the findings.
Dependability		Detailed descriptions of the context, research methodology, implementation and findings are provided to enable future researchers to repeat the study.
Confirmability	Reflexivity	A journal to enable author self-reflection was kept for the duration of the interview process. Information from all interviews and journal material was discussed between co-authors regularly. Thus, ensuring that any subjective biases that may arise do not influence data interpretation.
	Triangulation	Multiple data sources were used from different sectors of healthcare provision. Theoretical and researcher triangulation occurred through collaboration between authors who compared findings from different disciplines and positions.

Good-hearted versus Hate; Loving, Caring, Compassionate vs. Unloving, Uncaring, Not compassionate; and Compassionate vs. Unkind.

Sacrifice Versus Selfish When deciphering meanings associated with identified constructs, caregivers expressed how “taking care of the family” (Q27) and “seeing other people become better” (Q28) held more importance than their own needs, difficulties and aspirations. Furthermore, some caregivers explained the sacrifices they made regarding employment or career opportunities in order to prioritize the care of their loved one with dementia (Q27-Q31). In contrast, “selfish” was the dichotomous construct used by most of these caregivers to which meant people who don’t share are “greedy” and those who withhold care and love towards a loved one who is ill...old and needs your support is “selfish” (Q32-Q33).

Good Listener Versus Doesn't Listen; Good-hearted versus Hate Although one caregiver specifically identified qualities such “good listener” and “good-hearted”, as meaningful constructs, these qualities were expressed and/or demonstrated by most participants through the descriptions of their narratives. Therefore, these traits are listed as an independent subheading. Being a “good listener” meant being ready to listen without insult (Q34) and a “good-hearted” person meant “tak[ing] things in a very loving manner” and being genuinely loving (Q35). Conversely, dichotomous constructs that caregivers defined for the above-mentioned constructs were “doesn't take care” and “hate”, which meant “somebody who does not even listen”, does not consider what you have to say, is rude and dismissive (Q36).

Loving, Caring, Compassionate vs. Unloving, Uncaring, Unkind Caregivers who identified these constructs defined “loving, caring and compassionate” as providing food and care as acts of love, “not pretending to care” or “being judgmental”, but by being helpful, listening, patient, controlling your anger when “they make a mess or make a mistake” and “carry[ing] others' burdens... with them or for them” (Q37-Q39). In contrast, dichotomies of these constructs were defined as not having love or time for a loved one with dementia (Q40), being “unkind”, which meant being unfriendly, unobservant (Q41) and “a cold person, who is selfish” (Q42).

Theme 3: The Emotionally Resilient Caregiver

In keeping with the Emotional category of the CSPC, this theme presents identified constructs that twenty caregivers chose from their narrative sketches and the meanings thereof that demonstrate emotional resilience. These dichotomies are presented as subheadings namely, *Strong versus Weak; Cope versus Not coping; Tolerating versus Not accepting; Heals versus Sick; Positive and Optimistic versus Hopeless and Regressing*.

Strong Versus Weak This pair was frequently cited among caregivers, secondary to ‘caring’ constructs. Caregivers who identified “strong” as a meaningful construct defined this term in various ways. Being strong meant a lack of fear and being able to persevere when faced with adversity in order to “deal”, “complete” and “pass difficult things” to “come out stronger” without being “destroy[ed]” by their challenges (Q43-Q47). On the other hand, caregivers used the term “weak” to define what *not being strong* would be like. Being weak meant the presence of fear and a struggle to accept “the situation” (Q48), or “see things in a different perspective” (Q49), “you cannot reach your goals, you cannot complete tasks” (Q50). For other caregivers, “weak” meant that they were unable to cope, problem-solve or “be strong” for themselves and others, which could lead to “depression” (Q51-Q52).

Cope Versus Not coping For caregivers, to “cope” meant assuming full responsibility to taking care and being in control of everything related to dementia caregiving

for the person affected and “to accept the situation as is” (Q53-Q55). “Not coping” on the other hand, would mean that caregivers will be unsupportive and “will be complaining” about their loved one “giving [them] stress” (Q56). Furthermore, as a caregiver stated: “*Not coping means they are stressed. They are depressed. They are not in control of their situation*” (Q57).

Tolerating Versus Not Accepting “Tolerating” to caregivers meant acceptance and understanding that there elements of their circumstances that cannot be altered even though it may make some caregivers uncomfortable (Q58-Q59). “Not accepting”, which was identified as the dichotomous construct, meant the inability to accept and understand what may be occurring within their environment which would lead to anger, sadness and chaos (Q60-Q61).

Heals Versus Sick One caregiver identified “heals” as a meaningful construct and “sick” as its dichotomous pair. This caregiver meant that kindness and emotional support are important elements that facilitate healing after realizing that “you can be sick emotionally” whilst taking care of your loved one with dementia - which leads to unhappiness (Q62-Q63).

Positive and Optimistic Versus Hopeless and Regressing These constructs have been merged due its similarity in meaning for caregivers. Being “positive” and “optimistic” meant “seeing the silver lining in the dark” (Q64) and “hoping that this shall come to pass” (Q65) and not losing hope easily – having “courage” (Q66). Conversely, caregivers defined the opposite of “positive” and “optimistic” as “hopeless” and “regressing” which meant “to give up easily” (Q67), a sense of hopelessness and a lack of purpose (Q68-Q69).

Theme 4: The Cognitive Aspects of Caregiving

This theme presents the main constructs that eleven caregivers identified to depict skills, abilities and knowledge in the context of dementia caregiving. This is in keeping with the Intellectual/Operational category of the CSPEC. Subthemes hereunder are presented as *Understanding versus Not Understanding and Knowledge versus Uneducated*.

Understanding Versus Not Understanding Caregivers defined “understanding” as the ability to “acknowledge” (Q70) and “understand the situation” – which referred to making sense of the dementia-related behaviours of their loved ones (Q71). This is important to avoid conflict between the caregiver and the care recipient due to “not understanding” as caregivers stated “that’s when the fighting starts, the yelling starts” which tends to become “abusive” (Q72). Furthermore, without understanding, caregivers may anger easily, “shout” at their loved ones without any awareness of the attention that [they] need or getting to know what [they] are going through” (Q73-Q74).

Knowledge Versus Uneducated One caregiver explicitly identified this construct pair, despite many caregivers alluding to the need for knowledge and education as they described and defined other constructs. “Knowledge” was defined by this caregiver as acquiring training to be able to apply the knowledge gained to managing their loved one with dementia (Q75). In contrast, being “uneducated” meant “not [being able] to do the right things,” hence this caregiver emphasized the importance of education, knowledge and practical strategies to employ to their daily caregiving role (Q76).

Discussion

This study constitutes part of a larger study designed to explore the lived experiences of Black African dementia family caregivers in a South African township (Mahomed & Pretorius, 2021). The purpose of this aspect of the study was to understand how dementia caregivers interpret their world in the context of caregiving through the personal constructs that they identified. Of significance, a primary objective was to allow for caregivers to make meaning and interpretations without any guiding questions or prompting from the researcher. Overall, our findings indicate three primary categories of the CSPC under which meaningful personal constructs were identified, namely *Moral*, *Emotional* and *Intellectual/Operational* (Feixas et al., 2002).

The majority of the caregivers in this study – all of whom were female – identified constructs related to the quality of care that they provided for their loved ones with dementia and evaluated them as moral virtues. This is interesting, considering that Nguyen (2021) also reported that all female caregivers “associated their role of primary caregivers with their moral standard” (p.12). *The Moral Caregiver* in the current study meant making a loyal, faithful and responsible (Hughes et al., 2002) commitment to “care” in a good, loving and attentive manner (Leocadie et al., 2020; Todorova et al., 2016; Zahed et al., 2019), being able to solve problems (Leocadie et al., 2020; Netto et al., 2009) and distinguish right from wrong. Furthermore, “taking care” meant being able to support their loved ones by meeting their daily grooming and personal needs and prioritizing hygiene (Kleinman, 2012; Todorova et al., 2016). The antithesis of these qualities would deem a caregiver ignorant, negligent, irresponsible, unkind and unempathetic – implying poor quality of care provided by a “bad” and “untrustworthy” caregiver. Although feelings of guilt were reported by family caregivers in Hughes et al. (2002) especially when they wavered in their responsibilities or struggled to cope, negative feelings of this nature and caregiving mishaps were significantly underreported among caregiver narratives in this aspect of the study (Scotland, 2015).

In keeping with the *Moral* category of the CSPC (Feixas et al., 2002), more than half of the caregivers in this study identified constructs that portrayed altruistic values which governed their responses to caregiving. More specifically, the notion of *The Altruistic Caregiver* reflected participants’ understandings that their own needs, struggles, feelings and ambitions are somewhat insignificant in comparison to their long-term commitment to caring for their loved ones with dementia – despite their

challenges (Nguyen, 2021; Todorova et al., 2016). Although similar meanings were elicited for constructs describing *The Moral Caregiver* above, the emphasis among these sets of constructs was the concept of selflessness (Netto et al., 2009). Being selfish, on the other hand was interpreted by caregivers as a person who withholds love, care and support, does not have compassion or genuine intentions and is unable to emotionally regulate or adapt to situations when difficult behaviours of their loved ones manifest. As studies have shown, these qualities have been identified as important elements to facilitate meaningful and positive caregiving experiences (Cheng et al., 2016; Leocadie et al., 2020; Todorova et al., 2016; Quinn et al., 2012).

The *Emotional* category of the CSPC (Feixas et al., 2002) was also a prominent area that depicted caregivers' interpretations of their emotional responses and psychological states in the context of dementia caregiving. According to caregivers, *The Emotionally Resilient Caregiver* possesses emotional and psychological capacities such as strength (Ashrafizadeh et al., 2021; Netto et al., 2009), perseverance (Leocadie et al., 2020), control (Dias et al., 2015), acceptance and tolerance (Cheng et al., 2016; Hawken et al., 2018; Todorova et al., 2016), hope (Cheng et al., 2016; Palacio et al., 2020) and courage, which are adaptive responses to the complexities and multitude of stressors associated with dementia caregiving (Zhang et al., 2020). In contrast, our caregivers perceived the antithesis of an emotionally resilient caregiver as one who is likely to endure negative psychological and emotional consequences such as the inability to cope, stress, anger and depression (Abreu et al., 2018; Basu & Mukhopadhyay, 2019; Krutter et al., 2020; Zhang et al., 2020).

Consistent with the *Intellectual/ Operational* category of the CSPC, some caregivers identified constructs related to *Knowledge* and *Understanding* which underscored the importance of making sense of dementia-related behaviours and obtaining education, training and practical tools. This was important for caregivers, because it meant being able to mitigate conflict, emotional insensitivity and facilitate competence (Ashrafizadeh et al., 2021; Cheng et al., 2016; Netto et al., 2009; Palacio et al., 2020).

Overall, the above-mentioned interpretations made by our caregivers lead to useful insights that can be linked to important psychological resources such as resilience, coping and adaptation to the caregiver role (Dias et al., 2015; Palacio et al., 2020) that is associated with higher levels of adjustment and well-being (Senturk et al., 2018). Furthermore, it has been documented in the literature that experiences associated with dementia caregiving altered the sense of self among female dementia caregivers in particular (Nguyen, 2021; Tuomola et al., 2016). Similarly, most female participants in this study appeared to hold clear, stable and positive views of themselves as dementia caregivers - indicating higher levels of adjustment and well-being (Campbell et al., 2003; Parise et al., 2019). Moreover, they conveyed a sense of mastery and self-efficacy (Cheng et al., 2016; Cox, 2013) as they evaluated the quality of caregiving tasks with a sense of pride, and made sense of their approach to caring for their loved ones with unconditional positive regard. Of note, meaning-making is considered a coping mechanism (Pearlin et al., 1990) by which caregivers experience their role as stressful, but rewarding (Zhang et al., 2020) - consistent with caregiver perspectives in this study. Taken together, these factors contributed to caregiver emotional and psychological resilience that is vital to sustain good

mental health and quality of life for both caregivers and their loved ones (Dias et al., 2015). Of interest, although social support has shown strong positive correlations to facilitating resilience among dementia caregivers (Hawken et al., 2018; Palacio et al., 2020; Senturk et al., 2018), the caregivers in this study demonstrated admirable emotional and psychological resilience with minimal social support as reported in Mahomed and Pretorius (2021). Perhaps the support services provided by *Alzheimer's SA*, which most caregivers utilized in this study (Mahomed & Pretorius, 2021), served to compensate well for this deficit.

Limitations

A limitation of the study could be the large sample size, especially for a qualitative, narrative approach such as the self-characterization sketch. Perhaps a smaller sample size or a case study design would have allowed for deeper reflection to elucidate the nuances and complexities of how caregivers interpret their world and understand themselves – not only in relation to dementia caregiving – but in exploring and navigating other aspects of their identities and conflicts that impact psychological adjustment, well-being and quality of care. Although this would have implications for generalizability, it would still be important due to the subjective, unique and infinite ways that individuals may construe their world. It would also be valuable to tailor this for therapeutic interventions and to meet caregivers specific needs.

Furthermore, the authors are mindful of the possibility that caregivers may have provided socially desirable responses to match what they think the researcher wanted to hear or to impress the researcher (Netto et al., 2009). Nonetheless, Kelly (1991) emphasized that “the proverbial customer is always right” (p.241) – giving less importance to whether what the caregiver expressed was correct or not but *how* this information is interpreted and described to the researcher. Perhaps self-characterization sketches should be incorporated with other structured PCT techniques for cross-comparison and to draw measurable inferences between constructs to ensure rigor, validity and reliability. Future studies should attempt to address these limitations.

Conclusion and Recommendations

To our knowledge, this is the first South African study to employ a narrative approach committed to understanding the manner in which family caregivers of dementia make sense of their world and interpret their role in the context of dementia caregiving. Using the principles of PCT (Kelly, 1955, 1991), our caregivers were able to achieve this by identifying meaningful personal constructs within their context of caregiving. Findings revealed that caregivers' interpretations of themselves was characterized by moral, emotional and cognitive attributes that led to correlates of adjustment and well-being. A sense of mastery, self-efficacy, strength, selflessness and unconditional positive regard characterized the most meaningful constructs of care within caregiver narratives in response to their loved ones with dementia.

These adaptive outcomes, despite the challenging, pervasive, complex nature of dementia and its manifestations, suggest psychological and emotional resilience, higher levels of adjustment and caregiver well-being.

While these findings signify hope and serve as ameliorating factors that may reduce caregiver burden and psychological distress that is usually associated with dementia caregiving, it is important to consider the impact of this level of engagement long-term. Over time, without adequate social support, respite or self-care, *The Moral, Altruistic and Emotionally Resilient Caregiver* may experience physical fatigue (Ashrafizadeh et al., 2021) and burnout (Todorova et al., 2016). In light of this, it is recommended that approaches to psychoeducational initiatives, emotional and psychological interventions and awareness campaigns include teaching caregivers how to self-care without residual feelings of guilt or selfishness. This would better orientate caregivers and encourage the importance of consistent exercise, rest, sleep, nutrition as well as reaching out for social support. Lastly, allowing caregivers the space to reflect on and harness their own personal resources would prove valuable in support groups, individual counselling or therapy to facilitate self-awareness and sustained coping and mental health.

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Data Availability The data that support the findings of this study are available from the corresponding author upon request.

Declarations

The authors have no relevant financial or non-financial interests to disclose.

Conflict of Interest There were no conflicts of interest.

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