

# Support needs of familiar caregivers caring for persons who are minimally responsive: an ecological system approach

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**Objective:** The main aim of this study was to identify the multidimensional support needs of familiar caregivers and to identify the lessons they had learned throughout the caregiving process.

**Background:** Persons who are minimally responsive require continuous medical care—either at home or at a care facility. The home context is often preferred as it facilitates the care process in a familiar environment and reduces adverse health outcomes, such as mortality. Home care of the person who is minimally responsive is often managed by familiar caregivers who support these individuals in all aspects of daily living. This caregiving experience may be burdensome for the familiar caregiver as increased physical, psychological, emotional, social, and financial requirements, and responsibilities could cause multidimensional stressors.

**Methods:** A qualitative descriptive design using 7 semistructured in-depth interviews was used with 7 familiar caregivers of persons who were/are minimally responsive. These participants were obtained from a private care facility and thematic analysis was used to analyze the in-depth interviews.

**Results:** The ecological systems theory was used to identify and link 11 themes with subthemes to the support needs reported by the caregivers. In addition, the results included the lessons learned by these caregivers from their caregiving journey.

**Conclusions:** From the findings of this study, it is clear that caregivers mostly experience challenges within the microsystem and mesosystem with limited challenges in other systems. These systems are, however, integrated and can impact the individual caregiver substantially. Health care practitioners, in particular, should be aware of caregivers' support needs and give them adequate support at home.

**Keywords:** Caregivers, family, health care, needs, support

## What is already known about the topic?

Familiar caregivers often experience increased physical, psychological, emotional, social, and financial challenges when caring for persons who are minimally responsive. These multidimensional stressors can have adverse effects on the carer's quality of life and subjective well-being and should be targeted by health care practitioners.

## What this paper adds

- This paper highlights the importance of providing family-centered care instead of conventional person-centered care. This is due to the person who is minimally responsive, functioning within a family, and assessment/intervention should not focus on the person in isolation.
- In addition, this study elaborates on the specific multidimensional support needs of familiar caregivers within multiple interacting systems.
- Furthermore, this paper adds that familiar caregivers want to act in the best interest of the person and respect their individual personhood, as well as their human dignity in various settings (eg, residential care and care facilities). This paper also suggests that familiar caregivers do not only perceive caring for persons who are minimally responsive as a burden but also have various enriching experiences that teach them valuable life lessons.
- This study also emphasizes the value of health care practitioners listening to the voices of familiar caregivers of persons who are minimally responsive. Especially, as there appear to be discrepancies between what familiar caregivers regard as best practice and what health care practitioners regard as best practice.

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## Implications for practice, theory, or policy

The findings of this study elaborate on the multidimensional support needs of familiar caregivers within multiple interacting

systems. In addition, the focus has shifted from the conventional person-centered care model to a more family-centered care model. These components are important to note for health care practitioners as these practitioners need to provide holistic treatment that carries over from one context to another. The importance of advocating for persons who are minimally responsive is emphasized, as well as educating familiar caregivers, health care practitioners should especially target the familiar caregivers on what to expect during the process, making appropriate referrals, and providing practical strategies that may improve their caring experience.

## Introduction

Persons who are minimally responsive require continuous medical care—either at home or at a care facility<sup>[1]</sup>. The minimally responsive state is described as the individual having clear behavioral signs of alertness, environmental, and self-awareness but an inability to maintain these behavioral signs consistently. Therefore, periods of alertness and awareness fluctuate. The home context is often preferred as it facilitates the care process in a familiar environment and reduces adverse health outcomes, such as mortality<sup>[2]</sup>. The care is then managed by familiar caregivers (eg, life partner, parent, child, relative, or friend) who support these individuals in all aspects of daily living. This caregiving experience may be burdensome for the familiar caregiver as increased physical, psychological, emotional, social, and financial requirements, and responsibilities could cause multidimensional stressors<sup>[2,3]</sup>.

This research aims to describe these multidimensional stressors according to the ecological systems theory, conceptualized by Bronfenbrenner<sup>[4]</sup> and adapted to a framework for care by Pask et al<sup>[5]</sup>. This theory describes stressors as integrated within multiple interacting social environments which change over time<sup>[6]</sup>. These systems include the microsystem (ie, characteristics related to the caregiver as a person and the relationship with the person who is minimally responsive), mesosystem (ie, interactions that occur among the familiar caregiver, the care facility staff, and health care practitioners), exosystem (ie, services and the system level components which the caregiver is not directly related to but that can influence their caregiving experience), macrosystem (ie, components related to how the societal and cultural contexts are embedded within the other systems), and chronosystem (ie, changes in needs, circumstances, and environment over time)<sup>[5]</sup>.

Familiar caregivers operate within a larger environmental context (ie, the exosystem) in which they interact with the person who is minimally responsive in the microsystem, as well as with medical practitioners in their attempts to access services, such as rehabilitation (ie, the exosystem). Interaction with extended family and friends (ie, the mesosystem), as well as with acquaintances and other members of the larger community while attempting to deal with disability stereotyping (ie, the macrosystem) might also be negatively affected<sup>[5,7]</sup>. Furthermore, caregivers may experience difficulty in maintaining their own social relationships with family and friends, as their time is consumed with their caretaking responsibilities<sup>[1,8,9]</sup>. Caring for a person who is minimally responsive may, therefore, lead to caregivers feeling inadequate, fearful, anxious, and depressed which may increase their psychological stress in the microsystem<sup>[9]</sup>. This may cause caregivers to lose hope, decrease

their quality of life, and result in isolation within the mesosystem<sup>[1,8,9]</sup>.

From this discussion, it is clear that familiar caregivers experience challenges across different systems over different periods of time (ie, the chronosystem). Identifying these challenges timeously will enable health care practitioners to provide adequate support and respite to reduce the perceived burden of care. The main aim of this study was, therefore, to identify the multidimensional support needs of familiar caregivers by focusing on the lessons they had learned throughout their caregiving process.

## Methods

The following section includes a description of the methodology used to conduct the research:

### Study design

A qualitative descriptive design using 7 semistructured in-depth interviews was used. The qualitative design was selected to ensure rich data descriptions were obtained to address the relevant aims.

### Participants and setting

Purposive sampling based on specific sampling criteria ensured that participants would be in a position to supply thick and rich descriptions of the multidimensional stressors that they experienced throughout their time of caregiving. The 7 adult participants within minimally responsive states were referred by health care practitioners [medical doctors and allied health care (speech therapist, occupational therapist, and physiotherapist)] working in private practice in South Africa. These health care practitioners provided services in acute care, aged-care facilities, as well as home care. Health care practitioners referred caregivers of patients experiencing fluctuating periods of minimal responsiveness based on the severity of the patient's diagnosis. The familiar caregivers had to be adults (older than 18 y) and care for an adult, with an acquired neurological disorder who had been in a minimally responsive state for at least 6 months, for a period of at least 2 consecutive hours a day (due to the location of care, eg, some were in a care facility and some were cared for at home) and should have done so for at least 6 months before the interview. The caregiver should also be literate and proficient in English. Familiar caregivers of both living and deceased persons with acquired neurological disorders were included. Table 1 provides descriptive participant information (n = 7).

### Data collection

After ethics approval was obtained, written permission was obtained from a private facility to sample participants. The practice manager of the facility informed 8 potential participants of which only 7 agreed to participate. Upon verbal consent, the potential participants contacted the first author telephonically. The first author then obtained written informed consent and scheduled an interview with the caregivers based on their convenience. Semistructured interviews were conducted with 7 familiar caregivers of persons who were minimally responsive through Google Meet (n = 4; due to the global coronavirus disease 2019 pandemic) or face-to-face (n = 3), depending on the participant's preference (data collection occurred during 2021).

**Table 1**

**Demographic information of familiar caregivers and the minimally responsive persons they were caring for (n = 7).**

Dyad	Participant number	Age (y)	Sex	Relationship	Home language	Diagnosis	Duration of care (h) provided	Duration of minimally responsive state	Setting	Therapy context	Referred by
Dyad 1	C1	63	Female	Wife	English	None	2	7.7 y	—	—	—
	P1	66	Male	Husband	English	Abscesses on the brain	—	—	Aged-care facility	Only in-patient rehabilitation during the acute phase	Medical doctor
Dyad 2	C2	40	Female	Daughter	English	None	2	2 y	—	—	—
	P2*	69	Female	Mother	English	CVA	—	—	Home care	Only in-patient rehabilitation during the acute phase	Medical doctor
Dyad 3	C3	62	Female	Mother	English	None	24	5 y	—	—	—
	P3	31	Male	Son	English	TBI	—	—	Home care	In-patient rehabilitation during acute care; out-patient rehabilitation	Speech-language therapist
Dyad 4	C4	54	Female	Daughter	Afrikaans	None	2	6 mo	—	—	—
	P4*	79	Male	Father	Afrikaans	Alzheimer disease	—	—	Home care	No therapy received	Medical doctor
Dyad 5	C5	57	Female	Daughter	English	None	2	4.5 y	—	—	—
	P5*	76	Female	Mother	English	Alzheimer disease	—	—	Home care	No therapy received	Medical doctor
Dyad 6	C6	54	Female	Daughter	Afrikaans	None	2	72 d	—	—	—
	P6*	83	Male	Father	Afrikaans	Alzheimer disease	—	—	Home care	No therapy received	Medical doctor
Dyad 7	C7	45	Female	Wife	Afrikaans	None	24	1 y	—	—	—
	P7	41	Male	Husband	Afrikaans	Alzheimer disease	—	—	Home care	No therapy received	Medical doctor

\*Deceased participants.

CVA indicates cerebrovascular accident; TBI, traumatic brain injury.

The online interviews were conducted at separate venues (the researcher was in a clinical context and the participant at their home) and the face-to-face interviews were conducted at the private facility, adhering to strict coronavirus disease 2019 protocols. An interview script consisting of both open and closed-ended questions was used to promote procedural reliability<sup>[10–12]</sup>. The duration of these interviews ranged from 29 to 90 minutes with a mean time of 54 minutes<sup>[13]</sup>. The first author made conversational notes and observations to record additional information and guide follow-up questions<sup>[14,15]</sup>. The interview started with introductions, followed by imparting the ethical guidelines, obtaining biographical information, asking questions relating to multidimensional support needs, and concluding by thanking the participants.

The face-to-face interviews were transcribed verbatim by the first author, whereas the Google Meets online platform provided an automated transcript of the audio recording. These transcripts were returned to the participants to individually review as part of member checking and to ensure that their perceptions were portrayed accurately in the research<sup>[16]</sup>.

### Data analysis

Upon feedback of member checking from the participants, the 6 phases for thematic analysis, as suggested by Clarke and Braun<sup>[17]</sup> were followed: (1) the 3 authors started by familiarizing themselves with the transcripts and reviewing the data to gain a deeper understanding of the participants' perspectives<sup>[18,19]</sup>, (2) data reduction was performed to systematically select only information that aided in addressing the main aim. This process was followed by inductive reasoning to categorize the data that occurred recurrently<sup>[18,20]</sup>, (3) the authors searched to identify similarities in the data and formulated themes<sup>[17]</sup>, (4) the authors collaborated to review and reflect on the coherence and applicability of the themes until a consensus agreement was reached<sup>[18]</sup>, (5) themes were defined and named in a constructive manner while also linking it to the ecological systems theory by plotting it either in the micro, meso, macro, exo, and/or chronosystem<sup>[4,18]</sup>, and (6) writing up the data to provide evidence of the identified themes by reporting compelling examples and relating these themes to the research question and aims<sup>[17]</sup>.

### Ethics approval

Ethics approval was obtained from the research ethics committee of the relevant institution. Written permission was obtained from the facility, as well as written informed consent, from all participants before data collection.

### Findings

The findings of this study are discussed according to the study's aim and first focus on the multidimensional support needs identified by the caregivers, followed by a description of the lessons they had learned during their caregiving journey.

#### *Support needs of familiar caregivers caring for persons who are minimally responsive*

Table 2 provides a layout of the specific support needs mentioned by familiar caregivers and analyzed according to the different systems outlined in the ecological systems theory<sup>[5]</sup>.

First, the microsystem is discussed, which refers to the characteristics of the person who is minimally responsive that may influence the caregivers' caregiving experience and for which they require support<sup>[5]</sup>. The microsystem included the personal relationship with the person, personal characteristics, psychological stressors, and physical, environmental, and financial concerns. All of the caregivers mentioned that their relationships with the person were important to them and that they required support to act in the best interest of the person in their care. Two caregivers also mentioned that they required support managing the person's behavior (especially aggressive behavior) and interpreting it as attempts to communicate with one participant noting "I really wish I could read my dad's mind and understand what he was trying to communicate to me" (C6). Caregivers stated that they experienced psychological distress with 3 caregivers mentioning that they specifically, had difficulty with the unpredictability of the caregiving process with one simply stating: "It was not easy" (C1). These caregivers also mentioned that they had various expectations of the caregiving process and of health care practitioners which were often not met. Three caregivers mentioned that their expectations were related to their personality, with one mentioning "I am a fighter and I will fight for my son" (C3). In addition, caregivers mentioned that they required support in adapting to the role of caregiver, as well as to their additional daily responsibilities, for example, "I had to look after the kids, cook dinner, and go to work. It was hard to then make time for him" (C7). All of the caregivers also mentioned they had significant financial difficulties due to expenses not covered by their medical aids.

Themes mentioned in the mesosystem refer to the interactions that occur among the caregivers, the care facility staff, and health care practitioners<sup>[5]</sup>. Two main themes that were impacted as mentioned by caregivers, included health care practitioners and social contacts. Caregivers expressed that they often perceived health care practitioners as not providing sufficient information: "The doctor did not tell me what was wrong with my mom" (C5). The caregivers also mentioned that they felt as if they were not being heard by health care practitioners with 2 caregivers stating that, "Nobody listened to me" (C1 and C5). Factors related to the caregiver's social functioning focused on their family and faith community shared experience with other caregivers in similar life experiences, and their ability to engage in social activities. Of these, the caregivers rated their ability to interact socially as most important. Even though most caregivers were able to interact socially, some mentioned that they became isolated (C4 and C6).

Within the exosystem, many caregivers reported that they were unable to access services or organizations that could provide additional support. These caregivers reported that the health care practitioners with whom they were in contact did not make appropriate referrals to other health care practitioners, which negatively affected their caregiving experience.

One caregiver spoke to the macrosystem when she reported that persons with acquired disabilities often experience prejudice from unknown communication partners as these individuals are either not informed or misinformed and, therefore, do not know how to communicate with a person with a disability.

Finally, caregivers mentioned aspects linked to the chronosystem such as the fact that their needs changed from the initial admission of the person who is minimally responsive to the critical care unit to the discharge phase, irrespective of whether the discharge was to a home or care facility. These changing needs

**Table 2**

**Support needs to be experienced by familiar caregivers during the care of persons who are minimally responsive as classified according to Ecological Systems Theory (Bronfenbrenner 1992; Pask et al 2018).**

System	Main themes	Subthemes	Verbatim examples
Microsystem	Relationship with the person who is minimally responsive	Changing person-caregiver roles and bond	<ul style="list-style-type: none"> <li>You have to work on your relationship with the person (C7)</li> </ul>
		Acting in the best interests of a person	<ul style="list-style-type: none"> <li>I really wanted to do what was best for my husband (C1, C7).</li> <li>I wanted to fight for my son because it was about him not about myself (C3).</li> <li>We wanted to provide the best care for my dad because he was a good person (C4 and C6).</li> <li>I wanted to help my mom maintain the quality of life that she had before she got sick (C2 and C5)</li> </ul>
		Managing aggressive behavior in a person	<ul style="list-style-type: none"> <li>My dad used to get so aggressive and attack my mom and that was really hard for me to see because you can not keep them accountable as they do not understand what they are doing (C4).</li> <li>It was so hard adapting to the personality changes because my dad was so kind before he got sick but started showing aggression towards others during his sickness (C6)</li> </ul>
		Overcoming communication challenges with the person	<ul style="list-style-type: none"> <li>I really wish I could read my dad's mind and understand what he was trying to communicate to me (C6).</li> <li>Communication was a big problem for me and my husband (C7)</li> </ul>
		Personal expectations of the caregiving process	<ul style="list-style-type: none"> <li>Health care practitioners are supposed to support you, but they did not do it (C3).</li> <li>We did not know what the future held but no one communicated anything to us (C6).</li> <li>They did not tell me anything. I had to do my own research (C5).</li> <li>The people who were supposed to help us failed us (C6).</li> <li>We had no idea how we were going to get my mother home (C2).</li> <li>We had a lot of hope that he would recover but it just did not happen (C1).</li> <li>We thought if he was being cared for by a trained caregiver, he would show improvement but his physical state just regressed (C4)</li> </ul>
	Personal characteristics (personal characteristics that influence caregiving)	Personality	<ul style="list-style-type: none"> <li>I am a fighter and I will fight for my son (C3).</li> <li>I was doing this for my husband because he would have done it for me (C1).</li> <li>I had to do my best for my mom because she was very special to me (C2)</li> <li>Seeing your loved one fade away, how it is affecting him, and not being able to do anything was really stressful (C4)</li> </ul>
		Compassion fatigue	
		Frustration	<ul style="list-style-type: none"> <li>It is very frustrating when you are trying to look after your needs but the person just thinks of their own needs (C7)</li> </ul>
		Anxiety Self-doubt Self-blame Unpredictability	<ul style="list-style-type: none"> <li>My mom started hallucinating and this stressed me out because I did not know what was wrong (C5)</li> <li>I can not do this and I am not cut out for it (C1)</li> <li>I felt like it was my fault (C6)</li> <li>Not knowing what was going to happen next was really stressful (C1 and C4).</li> <li>The whole situation is so unpredictable and it forces you to realize that things are out of your control (C6)</li> </ul>
		Attitude	<ul style="list-style-type: none"> <li>I have no hope that he will improve we are just waiting for him to pass on (C1).</li> <li>I had to talk to myself to just remain patient with him (C6)</li> </ul>
Psychological stressors (emotional and psychological components experienced due to care)	Subjective experience of caregiving	<ul style="list-style-type: none"> <li>It was not easy (C1).</li> <li>My whole life changed and I had lost my purpose when she passed away (C2).</li> <li>I feel like I have been to hell and back (C3)</li> </ul>	
	Physical health of the caregiver	<ul style="list-style-type: none"> <li>I hurt myself when I had to lift him and my shoulder never really recovered (C4, C5).</li> <li>My dad almost fell as he had to carry my mom and lift her into the car (C2).</li> <li>I was my son's caregiver 24 h, 7 d a week. I was with him the whole time and only left to bath and eat. I barely slept and was worn out (C3)</li> </ul>	
Physical concerns (physiological wellness of the caregiver)	Living arrangements		<ul style="list-style-type: none"> <li>I wanted to place him in a care facility that I can visit daily (C1).</li> <li>I had to put her in a care facility as I was not able to look after her full-time (C5)</li> </ul>
Environmental concerns (components within the environment of the caregiver)			

		Environmental adaptations	<ul style="list-style-type: none"> <li>● The health care practitioner came to my house and made suggestions, such as putting a handle and bench in the shower and organizing a ramp for her wheelchair (C2).</li> </ul>
		Transport	<ul style="list-style-type: none"> <li>● I think they were not honest with us at the care facility as they locked the doors of the patient's rooms (C6)</li> <li>● Luckily our neighbor's car had a hoist for a wheelchair and we bought the car from him (C3).</li> <li>● My father really needed a hoist that could assist my mom to get in the car (C2)</li> </ul>
		Physical safety concerns related to a person	<ul style="list-style-type: none"> <li>● I was really concerned about the safety of my dad as he used to just walk out the door and not tell anyone where he was going (C6)</li> </ul>
		Assistance in adapting to increased daily responsibilities	<ul style="list-style-type: none"> <li>● I had to also look after both our parents while he was in the care facility (C1).</li> <li>● I had to go shopping for my dad to make sure he had all the things he needed (C6).</li> <li>● When you have children of your own it is often hard to focus on the care of your parent (C2).</li> <li>● I had to take care of the children and my husband as well (C4 and C5).</li> <li>● I really had to juggle getting the kids to school, cooking dinner, and making sure my husband was ok (C7)</li> <li>● We did not have the finances to get a caregiver for my mom(C5).</li> <li>● There were various additional costs that the medical aid did not pay (C1).</li> <li>● My mom did not have medical aid. So, she could not afford private doctors and specialized care (C4).</li> <li>● It was a big burden financially. I think my mom could have been better off if the lawyer had given her the right advice (C6).</li> <li>● The medical aid did not pay for transportation from one medical facility to another (C2).</li> <li>● We had to pay everything from our own account and are still awaiting funds from the Road Accident Fund (C3).</li> </ul>
	Financial concerns (financial burdens or needs of the caregivers)	Funding support	<ul style="list-style-type: none"> <li>● Finances were a burden but we thought communication was a bigger burden (C7)</li> <li>● She explained why my husband needed physio but did not seem interested as she mentioned that he would not improve (C1).</li> <li>● The doctor did not tell me what was wrong with my mom (C5).</li> <li>● I had to organize my own MRI and CT scans with other doctors as the doctor treating my son just spoke to me on his discharge and not during his hospital stay (C3).</li> <li>● The health care practitioner did not tell me what she was doing with my dad in therapy (C6).</li> <li>● Nobody told us what to do next or what to expect we were very unprepared (C2 and C7)</li> <li>● I did not feel supported by the health care practitioners (C1, C2, and C7).</li> <li>● The speech therapist got impatient with my son as he spit out his yogurt. She did not realize that he hated the flavor of it (C3).</li> <li>● It seemed like they were performing Chinese torture on my son during the splinting of his knee (C3)</li> <li>● Nobody listened to me (C1 and C5).</li> <li>● They did not even ask me how I was doing (C3)</li> </ul>
Mesosystem	Health care practitioners (health care person providing support to the caregiver)	Limited provision of information	<ul style="list-style-type: none"> <li>● Facilitators: involvement</li> <li>● My husband was very supportive and always understood when I said I needed to go see my mom/dad (C5, C6).</li> <li>● My parents also went to see my husband (C1).</li> <li>● My family supported me through the process and they were very involved (C7)</li> <li>● Barriers: Conflict</li> <li>● My brother took my mom to the doctor but he did not tell me anything about the appointment and just said nothing was wrong. He did not contribute financially towards my mother's care, I had to take all the responsibility (C5)</li> </ul>
		Perceived level of care provided by health care practitioners	<ul style="list-style-type: none"> <li>● Facilitators: involvement</li> <li>● The people at church really understood my mom's condition and they were so patient with her. They also came to our house and supported us by providing meals and just being there for us (C5)</li> </ul>
		Not being heard	
	Social contact (experiences of social entities and relationships influencing the caregivers' experience)	Family	<ul style="list-style-type: none"> <li>● Facilitators: involvement</li> <li>● The people at church really understood my mom's condition and they were so patient with her. They also came to our house and supported us by providing meals and just being there for us (C5)</li> </ul>
		Faith community	

**Table 2**

**(Continued)**

System	Main themes	Subthemes	Verbatim examples
108	Exo system	Access to other caregivers with shared experience	Barriers: Conflict <ul style="list-style-type: none"> <li>● My parents had contributed to the church a lot and were always involved in charitable activities. However, the pastor did not even come to see my mom during my dad's illness and did not support her at all (C6)</li> <li>● There was one lady whose son was in the bed next to my husband. She really supported me. She would send me updates if I were not there to make sure I knew what type of care my husband was getting (C1).</li> <li>● There was a lady that was recently widowed and she started talking to my dad because she knew my mom had passed away. This seemed to help her to process the grief of her husband's passing (C2).</li> <li>● The nurse who looked after my son used to WhatsApp me to send me updates on how my son was doing. This made the caregiving experience a lot better (C3)</li> </ul>
		Ability to interact socially	<ul style="list-style-type: none"> <li>● I could continue my social activities because my mom was in a care facility (C5).</li> <li>● My mom became so isolated because she could not go out anymore as my dad would embarrass her (C4, C6).</li> <li>● I still had to visit my husband daily but I could continue with normal living (C1).</li> <li>● I really tried to include my son in our family gatherings and would take him to a tea garden to get out a bit. I did not really visit with many friends during this time (C3).</li> <li>● We often invited my parents for dinner so my dad could get a break and would then spend time with my mom (C2)</li> </ul>
	Macrosystem	Limited access to services	<ul style="list-style-type: none"> <li>● We did not know who to contact and where to obtain the services (C1 and C2).</li> <li>● I wish I knew of a place where we could get trained caregivers for my dad (C4).</li> <li>● I wish the medical aid paid for a speech therapist to assist my mom with her communication (C5)</li> </ul>
		Community stereotypes	<ul style="list-style-type: none"> <li>● People used to think my husband was stupid because he was not able to communicate and I would think you can talk to him like a normal person he is not stupid (C7)</li> </ul>
Chrono system	Changing needs of caregivers	<ul style="list-style-type: none"> <li>● All caregivers need to change over time according to the specific stage of recovery that the person is in (C1–C7)</li> </ul>	

were directly related to the level of recovery of the person as it changed over time.

**Lessons learned from the caring process**

The caregivers experienced significant burdens of care, particularly referring to the unfamiliarity and unpredictability of the person’s diagnosis, as contributors to their burden. Even though these caregivers experienced the burden of care, they spontaneously expressed that this process had taught them various valuable life lessons that shaped the lens through which they viewed the world. Figure 1 includes the quotes of these life lessons which sparked a greater appreciation of life within these 7 caregivers.

**Discussion**

Holistic care should focus on the hopes and goals of both the person who is minimally responsive, as well as his/her familiar caregiver, as the person continues to function within a family unit<sup>[7,21]</sup>, irrespective of their medical diagnosis. Health care practitioners, therefore, need to support both the person and the familiar caregiver within multiple integrated systems to ensure holistic care and to facilitate improved quality of life (ecological systems approach)<sup>[21]</sup>. Providing support for the familiar caregiver is especially important when caring for persons who are in a minimally responsive state. These persons’ recovery rate often occurs over longer periods of time which requires various personal sacrifices from familiar caregivers<sup>[22]</sup>. Personal sacrifices by the familiar caregiver may cause various burdens of care, as well as decreased health-related quality of life for them. According to Chinner et al<sup>[22]</sup>, the burden of care of the familiar caregiver may be further exacerbated when the person in a minimally responsive state experiences behavioral, communication, and social challenges<sup>[22]</sup>. In addition, the burden of care differs from

when the person is responsive as the person has less severe behavioral, communication, and social challenges.

These challenges were mentioned by familiar caregivers within this study and related specifically to the caregiver’s relationship with the person who is minimally responsive. Earlier research<sup>[23]</sup> confirms that the caregiver’s relationship with the person is severely impacted by the personality changes related to the person’s acquired disorder, as well as the nature of the disorder that results in behavioral, communication, and social challenges, which were difficult for the caregivers to adapt to. Although these challenges were difficult for caregivers, the caregivers included in this study maintained their stance of wanting to act in the best interest of the person being cared for.

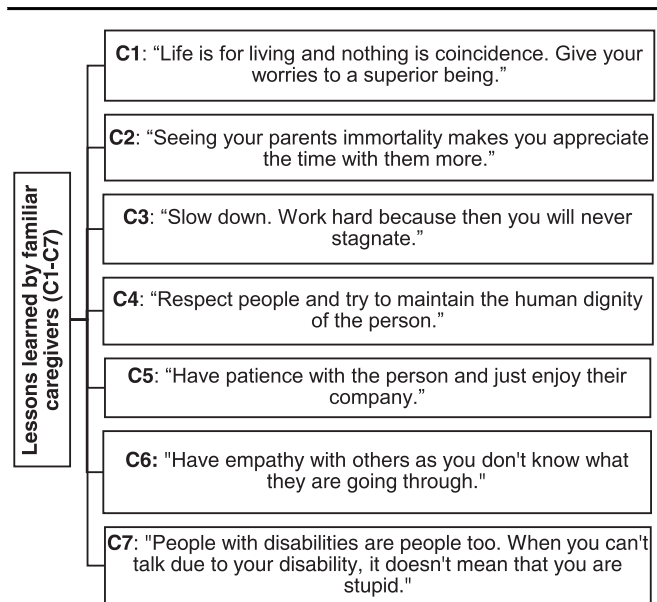
Furthermore, from the findings of this study, it became apparent that substantial discrepancies existed between familiar caregiver’s conceptualization of best interests and health care practitioners’ perspective on best interests (as perceived by caregivers). Lond and Williamson<sup>[24]</sup> mention that such discrepancies may occur due to caregivers’ expectations of health care practitioners and may result in a negative caring experience.

According to caregivers, their negative caring experience may be changed or ameliorated due to the caregiver’s resilience, personality, or coping strategies, but cannot be completely alleviated without adequate support from the health care practitioners. While some caregivers mentioned health care practitioner involvement during the care process, others experienced health care practitioners as unengaged, providing limited information, as well as not providing practical strategies for use during the daily care of the individual. Similarly, Eaton et al<sup>[25]</sup> mention that negative perceptions of health care practitioners’ involvement may be due to poor communication between caregivers and health care practitioners that could lead to misunderstandings, misperceptions, and missed opportunities for health care practitioners to provide adequate support. In addition, caregivers’ perceptions of inadequate support from health care practitioners caused significant psychological distress which resulted in an increase in the caregivers’ burden of care, as well as their decreased adherence to intervention protocols<sup>[25]</sup>.

Other components that added to caregivers’ psychological distress were their feeling of not being heard, as well as the caregivers’ poor social involvement<sup>[26]</sup>. Some caregivers mentioned that they were socially engaged, whereas some felt that they became socially isolated, experienced associative stigma (embarrassment over the behavior of a person), and hence avoided social gatherings due to the community’s perception and behavior towards persons with disability<sup>[26]</sup>. Mfofo-M’Carthy and Grischow<sup>[26]</sup> mention that due to the community’s behavior towards these persons, it can be determined that disability is socially constructed by the intentional/unintentional attitudes and barriers of society rather than the impairment itself.

**Limitations**

Possible limitations of the current study included a small sample size which consisted of a broad population. Despite the small sample size, participants provided rich and comprehensive data, stating that they valued the opportunity to reflect on their caregiving practices. Another possible limitation included the addition of multiple aetiologies for the minimally responsive state. However, the variability in aetiologies focused on caregivers as the experts in the care of the person and also assisted in



**Figure 1.** Examples of valuable lessons learned during the caregiving process as expressed by caregivers themselves.

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identifying similarities within the process of care. This study also only focused on individuals who were able to afford private care and the future should include public health care in South Africa, as well as caregivers from culturally, linguistically, and different religious groups.

## Conclusion

From the findings of this study, it is clear that caregivers mostly experience challenges within the microsystem and mesosystem with limited challenges in other systems. These systems are, however, integrated and can impact the individual caregiver substantially. Health care practitioners, in particular, should be aware of caregivers' support needs and give them adequate support at home. In addition, health care practitioners should adopt a family-centered approach toward treating these persons and listen to the voices of familiar caregivers to ensure that they perceive themselves as part of the care team and as key stakeholders in the care of persons who are minimally responsive.

## Future research

Future research could include retrospective interviews with persons who regained consciousness about their recollections during this time. Furthermore, research should focus on the holistic support of caregivers from initial admission to the critical care unit to being discharged home. Research should specifically target supporting caregivers at home, as well as the barriers and facilitators that add to the stress and burden of care. Interviews with caregivers could also include what their expectations are for the patient's recovery at the early stages of their diagnosis and how this can on the person-partner's experiences.

## Ethical approval

Ethics approval was obtained from the research ethics committee of the relevant institution (HUM029/0720). No data collection commenced without prior permission and consent from relevant stakeholders.

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## Author contributions

All three the authors were involved in the conceptualization of the manuscript. The first author conducted the data collection procedures. The three authors contributed equally to writing the introduction, method, findings and discussion.

## Conflict of interest disclosures

The authors declare that they have no financial conflicts of interest with regard to the content of this report.

## Data availability

Data described in the manuscript, code book, and analytic code will not be made available due to ethical considerations and the confidentiality of participants.

## Research registration unique identifying number (UIN)

The following number was given to the study upon ethics approval from the institution (HUM029/0720).

## Guarantor

None.

## Declaration of Generative AI and AI-assisted technologies in the writing process

No AI tools/services were used during the preparation of this work.

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