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A Role-Needs Framework: Rethinking Support for Informal Caregivers for Alzheimer's Across the Global South and Global North

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ABSTRACT

Objective: Caregivers play an essential role in supporting people with Alzheimer's disease globally. User-informed research is vital to developing trans-cultural guidelines for dementia support organisations. While coping strategies of caregivers are well researched, the 'coping-effectiveness' framework falls short of representing all caregiver needs. Our aim was to develop a robust and inclusive, globally applicable framework of caregiver-informed support needs.

Methods: In partnership with Alzheimer's Disease International and Roche, we conducted qualitative online semi-structured interviews with 34 family caregivers from the Global North (UK, US) and Global South (Brazil, South Africa) in the COVID-19 context. Participant-generated photographs helped encourage discussions of hidden contextual issues. Iterative inductive narrative analysis of interviews and photographs was carried out with input from global and national charity and industry sectors.

Results: We identified a framework of four cross-cultural caring approaches with implications for support: (1) *Empathising*, using emotion-focused strategies to develop strong expertise and coping skills, with time specific information, psychosocial and peer support needs. (2) *Organising*, using problem-focused strategies, with strong narratives of expertise and advocacy which benefited from early structured information and professional confirmation. (3) *Non-identifying* caregiving, where daily aspects of caring occurred without specialist knowledge and expertise, and caregivers sought assistance in managing disease-related support. (4) *Reluctance*, where struggling with unwanted caring responsibilities meant caregivers looked to professionals to carry out daily care.

Conclusion: Our findings move beyond the 'coping-effectiveness' framework of support to suggest a novel 'role-needs' framework. Our approach supports inclusive ways of tailoring support to fit individual caregiver circumstances globally.

1 | Introduction

Family caregivers are relied on globally to support the wellbeing of people with Alzheimer's [1]. They are forecast to provide the equivalent of 65 million full-time unpaid jobs by 2030

worldwide [2]. Existing literature emphasises the need for diversity of support and a person-centred approach [3, 4] but suggests that support for caregivers is inconsistent and often falls short in meeting caregiver's needs [2, 5]. While WHO is calling for countries to develop efficient care pathways, care

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Summary

- *Primary question:* Informal caregivers provide invaluable support for people with Alzheimer's globally. Good informal care can significantly improve the quality of life for both caregivers and cared for. However, the caregiver burden means many struggle, and their support needs are variable and complex. Existing research puts support for caregivers within a 'coping-effectiveness' framework, which creates an unhelpful category of 'non-copers'.
- *Main findings:* We found four caring approaches with implications for support needs. Two of these (Empathising role and Organising role) are already recognised within the 'coping-effectiveness' framework. However, the other two (Non-identifying role and Reluctance role) have not yet been given adequate consideration.
- *Implications:* Our findings suggest a more inclusive and globally applicable framework for understanding caregiver support needs. Our unique cross-cultural study builds on existing research and suggests a 'role-based' model better represents the diverse range of caregiver needs. Acknowledging 'Reluctance' and 'Non identifying' roles may help to tackle stigma and make caregivers feel better represented.

regimes and policies are ubiquitous by their absence (WHO global status report 2021) [6]. Regional disparities do, however, exist: while Brazil and South Africa have no national dementia strategy [7, 8], the UK and US have national dementia programs [9, 10]. Globally, most support for caregivers exists in high-income countries, and even then, service provision is inconsistently applied based on social and geographic factors [2]. Ideals of holistic and tailored support can be difficult to operationalise [11], and are open to interpretation at the point of delivery [2].

One emerging solution in the international arena, generic online self-help guidance and support for caregivers [12–14], is viewed as an accessible and economical way to get information and support to caregivers, that can be adapted to national and local contexts [15, 16]. Modular based online educational packages [17, 18] train caregivers to cope with common challenges and offer strategies for better caring. However, such interventions typically draw on an ideal-type caregiver, and reflect a bias in the wider literature for interventions promoting self-help and caregiver resilience [19, 20]. These resources assume a baseline of coping, capacity, time, and motivation, underpinned by a desire for self-efficacy in the caring role, that may not reflect the lived experience of many caregivers globally. This emphasis on coping capacity may, inadvertently, contribute to stigma, shame and blame [21]. Evidence shows that caregiving has a significant psychological, social, physical, financial and emotional impact on family members, with caregivers adapting to unpredictable disease progression, as well as contending with stigma, financial worries, and relationship adjustments [22–24]. The COVID-19 pandemic resulted in additional challenges for caregivers, who reported experiencing more sadness, worry, and stress, in addition to increased social isolation, financial stress and difficulties accessing usual support [5, 25–27]. These changing social and demographic factors, and

the physical and mental health of the caregiver, negatively affect support service use [21].

Each caring journey is unique [28], and support needs may be impacted by a variety of factors: including gender [29–31], caregiver age [32] relationship type [33–35], relationship quality [22, 36–38], and cultural beliefs [39–43]. These factors help reveal the diverse needs of caregivers. Yet may not represent the whole or most important aspect of an individual caregiver's experience, leading to false presumptions about caregiver needs. An alternative way of tailoring support is to examine how informal caregivers understand and identify with their caring role, and to work with caregivers' existing or preferred caring strategies.

In their transactional theory of stress and coping, Lazarus and Folkman [44] identify two broad strategies used by individuals to cope in stressful situations—problem-focused and emotion-focused strategies. There is now extensive literature exploring these two approaches in the context of informal caregiving for a person with Alzheimer's [45]. Emotion-focused coping strategies used by caregivers include acceptance, humour, positive reframing, and drawing on religious/spiritual beliefs and emotional support. Problem-focused strategies most commonly include actions such as seeking advice from others and coming up with pro-active plans of action [46–48]. Both are seen as more effective and helpful in supporting longer term psychological wellbeing when compared with, for example, avoidance and denial [49]. However, situating support needs within a framework of 'coping' and its implied opposite, is problematic if we want to work towards an inclusive and blame-free support provision.

Uniquely, the current study aims to develop a holistic framework that uses a broader conceptual container—the way a caregiver constructs their caring role—to understand their support needs. By support needs we mean not only the multiple types of support people need across varying dimensions (e.g., physical support, respite, financial, information, counselling, peer support, access to medical expertise, advocacy), but also when they need any of these supports and which are a priority and when. We develop a conceptual framework from the shared lived experiences of caregivers across the Global North and Global South, so as to better inform global support provision for people informally caring for a person with Alzheimer's.

2 | Materials and Methods

2.1 | Study Design

The study used qualitative online semi-structured interviews with participant-driven photo-elicitation, in which photos chosen by participants are woven into the interview process to reveal contextual and frequently unspoken aspects of their lived experiences, bringing hidden stories and emotions to life via triggered memories [50–52].

We included two study sites in the Global North (United States and United Kingdom) and two in the Global South (South Africa and Brazil). In the Global South, involvement of diverse caregivers and people with Alzheimer's in research can be challenging due to stigma, lack of dementia awareness and late diagnosis [53, 54]. To address this, we worked with local ADI member organisations, from study conceptualisation and design to recruitment of participants and local researchers to help build capacity. This capacity-building was extended beyond the study with partners in Brazil who co-created multi-media resources to disseminate the findings. Our study design incorporated key criteria for quality qualitative research including rigour, ethics and coherence between methods and findings, and reported using the COREQ criteria for qualitative research guidelines [55] (Supporting Information S1).

2.2 | Selecting and Recruiting Participants

Thirty-four participants from four countries were interviewed between April 2022 and February 2023 (Supporting Information S2). Participants were recruited through an online survey which explored caregivers' wellbeing and access to formal and informal support during the COVID-19 pandemic. Survey recruitment was through social media campaigns led by local ADI member organisations and specialist portals for people interested in research in the United Kingdom (Join Dementia Research, JDR) and United States (TrialMatch). Survey participants were asked to provide personal details if they were interested in taking part in an online interview about their experiences of caregiving. In South Africa we recruited directly through local and grassroots Alzheimer's support charities (Bessie Makatini Foundation and regional offices of Alzheimer's South Africa) as we were not able to recruit effectively through online channels.

We used purposive sampling to establish heterogeneity across gender, ethnicity, age, relationship to and functional severity of the person with Alzheimer's and number of years caring (see Table 1). We invited 12–25 participants in each country until we reached our target ($n = 10$), except for South Africa ($n = 4$). Despite working with local organisations and researchers, the online design of the study proved a greater barrier to participation in South Africa due to restricted electricity/wifi availability and barriers around technology use. Response rates to interview invitations varied between countries (UK 83%, Brazil 47%, USA 37%, South Africa 16%).

2.3 | Procedure and Ethics

Volunteer participants who were sampled were sent further information about the study and an online consent form. Following consent, participants received a photo-upload link and interview video call link. All participants were asked to take between two and six pictures of objects or places (but not people) that they felt captured their feelings or experiences of being a caregiver. Verbal consent (documented and shared with the participant) was obtained for the use of each photograph at the

end of the interview. A shopping voucher was given to participants (US, UK and South Africa) following the interview as a token of appreciation.

The study was approved by the College of Liberal Arts & Sciences Research Ethics Committee, University of Westminster (ETH2122-0432) and CONEP (Comissão Nacional de Ética Em Pesquisa), Brazil (ref: 56747222.2.0000.5231).

2.4 | Data Collection

Online semi-structured interviews incorporating photo elicitation [50–52] were carried out by the Research Fellow (FK), or by local researchers in Brazil and South Africa (experienced female qualitative interviewers), in the participants' preferred language (English, iXhosa, Zulu, Brazilian Portuguese). FK trained and supported local researchers and has prior experience of living and conducting research in the Global South. The interviews (20–80 min) were audio recorded, professionally transcribed, and translated into English. All transcripts were fully anonymised, and participants invited to select a pseudonym. Participant photographs and questions in the Topic Guide were used to guide the interview discussions (Supporting Information S3). The Topic Guide included questions relating to the caregiving experience, the impact of COVID-19, coping as a caregiver, accessing support and information, and participant reflections on their caregiving journey.

2.5 | Data Analysis

Using NVivo software [56, 57], interview transcripts ($n = 34$) were coded and analysed by FK, an experienced qualitative researcher, and discussed regularly with the co-authors. Each section of the interview relating to discussion of a photograph was coded thematically and then linked to the relevant photograph. When themes were analysed, any sections of coded text that had a photograph were also analysed. Pictures could later be connected to the interview text while sharing findings and writing up. We used a two-step process of: (1) developing and analysing themes in the data using thematic analysis [58]; (2) a narrative analysis of the stories people told about those themes, what they revealed about their identities and the meaning they gave to their experiences [59–61]. During the thematic analysis, meta-themes from the Topic Guide were applied to the data to produce a thematic coding frame (COVID-19, Coping, Support and information, Caring experience). Sub-themes were then identified using inductive analysis. We coded the data by country as well as across all countries to identify any similarities and differences in the emerging codes. A selection of transcripts was read by and discussed within the wider research team (with a range of expertise in medical sociology, health psychology, neuropsychology and lived experience) to develop inductive themes. In addition, the first author and the local researchers in South Africa and Brazil kept a reflexive journal and discussed and debated emerging issues regularly with other members of the research team in line with best practice guidelines for qualitative reporting [55].

TABLE 1 | Summary of sample demographics across countries.

	Country			
	UK (<i>n</i> = 10)	US (<i>n</i> = 10)	South Africa (<i>n</i> = 4)	Brazil (<i>n</i> = 10)
Gender				
Female	6	8	4	6
Male	4	2	–	3
Other		–	–	1
Ethnicity				
Asian	1	1	1	–
Black or African origin	–	3	2	1
Hispanic (US)	–	1	–	–
White	9	5	1	6
Mixed/indigenous (Brazil)	–	–	–	3
Age				
27–50	2	4	2	5
51–65	4	2	2	4
66–90	4	4	–	1
Relationship				
Spouse	4	3	–	1
Parent	6	4	4	7
Other family member	–	3	–	2
Functional severity of person with Alzheimer's				
Some difficulties	3	3	–	2
Notable difficulties	–	–	–	1
Manages simple activities	4	2	2	1
Cannot function independently	3	5	2	6
Main carer				
Yes	8	8	4	9
No/not sure	2	2	–	1
Living together				
Yes	8	7	3	8
No	2	3	1	2
Years caring				
0–3	4	1	3	2
4–6	2	4	–	4
7+	4	5	1	4

Two sub-themes emerged from the thematic analysis as dominant ('Caring role' and 'Relationships'). During the narrative analysis phase, data coded to these themes were analysed in depth to better understand how caregivers narrated their experiences of the caring role and their relationship with the person with Alzheimer's. We used deconstruction to examine the language used in its social and cultural context and interpretation for meanings and implications to understand how participants constructed their identities. Finally, we used comparative analysis to compare and contrast different narratives within the dataset to identify commonalities and differences. Four dominant types of

narrative were identified from our analysis (Empathising, Organising, Non-identifying, and Reluctance). Key characteristics in each narrative were explored using visual maps, incorporating quotes and pictures from the data. These were shared, presented, and debated at regular intervals with the research team and more widely (see below) to increase rigour. Mapping of the data and participant photographs were shared in meetings with ADI, Roche and local partners for reflections and debate during phase 1 and 2.

To further ensure the relevance of our analysis for patient and support organisation stakeholders, the findings were presented

and discussed at several international meetings of Alzheimer patient organisations, including the Finding Alzheimer’s Solutions Together (F.A.S.T.) Council formed to bring Alzheimer patient organisations and Roche together to better understand the perspectives and needs of patient communities.

3 | Results

We identified a framework of four cross-cultural approaches to caring, with implications for support needs: Empathising, Organising, Non-identifying and Reluctance (see Figure 1). In the first two approaches, caregivers most strongly identified with the term ‘caregiver’ and developed a strong sense of expertise in the caring role over time. In the third and fourth approaches, family members did not self-identify as ‘caregivers’ and sought to maintain family relationships that pre-dated diagnosis. While the former sought support (emotional and practical) to help them become better caregivers, the latter typically sought the help of others to monitor or carry out the caring duties to help them maintain their pre-diagnostic family

relationships. Additional extracts and photographs can be found in Supporting Information S4 and S5.

3.1 | Empathising and Organising

Our data revealed two dominant narrative approaches to caregiving. An ‘Empathising’ narrative involved constructing the caring role through a feeling lens. An ‘Organising’ narrative entailed constructing the caring role through a thinking lens. Both Empathising and Organising narratives included ideals of expertise and coping. Although caregivers generally ‘muddled through’, there was a sense of direction and an attuned knowledge of their loved one’s health and wellbeing (‘I would say 90% of the time we get to the toilet because I’m watching his body language all the time’ Sally, UK). There was also a sense of pride (‘I’ve managed to give five people so far, the best end of life that they wanted (...), which I’m very proud of’ Angelina, UK) and moments of joy/fun and laughter (‘we both started laughing...she was always very playful’ Col, US). Empathising and Organising also coincided with gratitude for the caring role,

Empathising – “Put yourself in that person’s shoes”	
Role	Support needs
<p><i>Construct role through feeling lens</i></p> <ul style="list-style-type: none"> • Acts of loving care and compassion • Wanting to be a better carer, personal development/growth 	<p><i>Need to prioritise own emotional needs</i></p> <ul style="list-style-type: none"> • Psychological, community and peer support • Time-relevant information to understand loved one’s needs
Organising – “I’m a pretty good expert now”	
Role	Support needs
<p><i>Construct role through thinking, problem-focused lens</i></p> <ul style="list-style-type: none"> • Challenges seen as structural – machinery of caring, routines • Wanting to grow their skills, akin to a professional role 	<p><i>Need professional confirmation</i></p> <ul style="list-style-type: none"> • Structured information and training to build on existing skills • Professional advice and support when requested
Non-identifying – “do everything I can...there’s nobody else”	
Role	Support needs
<p><i>Caring role framed as an extension of pre-diagnosis relationship identities – do not identify as ‘caregivers’</i></p> <ul style="list-style-type: none"> • Lack of knowledge, expertise and support • Unprocessed emotions leading to confusion and guilt 	<p><i>Need someone that “has your back”</i></p> <ul style="list-style-type: none"> • Professional oversight of loved one’s care and health needs • Someone to advocate on their behalf
Reluctance – “I didn’t sign up for this”	
Role	Support needs
<p><i>Lack capacity and willingness to be a caregiver</i></p> <ul style="list-style-type: none"> • Caring duties draining, feel trapped and unprepared • Lack of support and expertise 	<p><i>Need others to take responsibility</i></p> <ul style="list-style-type: none"> • Professional and practical support – paid carers, day care, care homes • Support to come to terms with diagnosis and life disruption

FIGURE 1 | ‘Role-needs’ framework for understanding different caregiver needs.

which could be rooted in spiritual beliefs ('God has some blessings planned for me on the other side of this journey'. Lorraine, US). The experience opened new doors for some. After his grandfather passed away Michael realised he was good at caregiving and trained to be a professional caregiver.

3.1.1 | Empathising Narratives: 'Put Yourself in That Person's Shoes'

Compassion and love for the person with Alzheimer's was a cornerstone of the empathising narrative ('I love having her home' Lorraine, US). This included acts of loving care ('I also had that moment of beauty with her. I'd do her nails, cut it, dye her hair'. Camila, Brazil) and sharing in their loved one's joy. JLS found a particular CD that her mother-in-law enjoys 'that brings her eyes alive'.

Photographs of their loved one's hands in theirs were used by several participants to symbolise a close and loving bond, and lifelong commitment (Table 2.1). Caring in this way frequently resulted in a unique connection with the person with Alzheimer's ('even now the only person she listens to or tries to understand is only me' Anele, South Africa).

Initially, there were challenges involved in accepting what was happening to their loved one's health, as well as the adjustments needed to become a caregiver (Table 2.4). Empathising narratives thus involved information gathering in the early stages of being a caregiver to understand the disease and their loved one's experiences. Information could come from books, charities, online and ad hoc sources (Table 2.2 and 2.3). Over time, the relationship with their loved one itself became the centre of their learning experiences. While often beginning with little or no caring experience, these participants gradually developed skills and expertise, gaining insights into their own and their loved one's needs (Table 2.5).


Increased caring skills frequently meant giving their loved one more freedom, within limits, and adapting their own behaviours or practices accordingly. This involved trying to look at things from the person with Alzheimer's' perspective, and co-creating solutions with their loved one (Table 2.6). They reflected how establishing a feeling-based connection with their loved ones made things more pleasant for the loved ones and easier for them (Table 2.7).

Empathising allowed caregivers to view challenging situations or conflicts through the eyes of the person with Alzheimer's, casting behaviours that challenge as situational and co-regulated (affected by the caregiver's emotions and behaviours): 'sometimes you know, *you* can do some things which make them very angry' Michael, US. Respect and seeing the whole person, not the disease, was important: 'There's no use saying 'she's not here anymore'. She is, in a different way' Girassol, Brazil.

Empathising was associated with a strong narrative of personal growth and self-assurance, reinforced by the confidence of having gained enough experience to deal with whatever arose. Vida noted that while there was 'no way to predict' when her mother would become upset, she had strategies to cope and to keep her and her mother safe (e.g., agreeing with her in the moment).


Caregivers with strong empathising narratives need to pay particular attention to their own emotional needs. This was particularly relevant where empathising was dominant because of the emotional lens through which caring was constructed. Caregivers who were juggling caring with work or looking after children faced additional challenges: 'I mean, it's hard, it's like burning the candle at both ends...I'm constantly exhausted' Ellen, US. Further challenges included isolation and loss of identity, particularly for younger or adult-child caregivers who missed out on socialising with their peers due to their caring duties ('I'm living for her' Teresa, Brazil). Emotional regulation

TABLE 2 | Empathising approach: Illustrative quotes and photographs.

1		<p>'That's me and my mother. Demonstrating our love, despite the struggles, we remain firm, I go hand in hand with her, with love, thinking about providing the best. I won't always succeed, but I'll try and I'll always be with her, firm, with her firm and loving hands with me and I with her'. Bruna, Brazil</p>
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(Continues)

TABLE 2 | (Continued)

2		<p>'And so I felt like if I could absorb as much information as possible, it would be helpful, you know? So, even... like, helping me as a caregiver; helping me understand the disease; helping me, um, kind of explain, you know, what's going on to other people... for me, kind of, it was almost like an armour, like preparing myself for war. Reading these books; trying to absorb, you know, as much information'. Ellen, US</p>
3		<p>'I was a layperson at first, it was challenging. I didn't understand. I then randomly began looking up information to learn more'. Camila, Brazil</p>
4		<p>'it's initially really confusing, you're unsure if it's the person or the disease, you're still a little lost, and you're scared of what's happening' Vida, Brazil</p> <p>'At that time...I thought I was wasting my time there...I can now see how it was a stage of my life and my aunt's life'. Camila, Brazil</p>
5		<p>'At first, I used to walk around her, keep taking stuff from her, trying to put everything back in its space. And then later on, I realized that, you know, I'm actually gonna get, I'm actually going to get a mental breakdown, myself if I keep trying to run after her and take everything from her'. Anele, South Africa</p>
6		<p>'...and a lot of times, I would follow his lead, instead of trying to lead him, you know, just kind of let him do what he was comfortable doing and just be a... you know, obviously you're not going to send him in the wrong direction, but, you know, try to manage that, whatever he's trying to do'. Col, US</p>
7		<p>'...you have this bond, this affection, this respect, and this fondness. Without it, there is still the possibility of caring, but it becomes heavier for the caregiver, because the person who needs care doesn't want to be cared for by that person, because there is no connection or interaction, which makes it challenging for both'. Girassol, Brazil</p>
8		<p>'I gotta take care of myself first, otherwise I'm going to be very grumpy and not a very good caregiver'. Ellen, US</p>

was also a difficult challenge and people talked about needing help to process emotions via peer support, other family members, community groups or trusted friends. Some chose to work through their emotions by talking to a therapist: 'it's good to share some of those feelings and thoughts and knowing that you're not the only one having those'. Ellen, US. In time, people with strong empathising narratives generally became aware of the need to prioritise their own needs in order to be a good caregiver (Table 2.8).

3.1.2 | Organising Narratives: 'I'm a Pretty Good Expert Now'

Caregivers with strong organising narratives tended to construct their caring role through a 'thinking' lens. There was a close and continuing relationship with their loved one: 'So even though my mother is sick, she still gives me this strength...' Rosa, Brazil. However, organising caregivers were more likely to see challenges as structural: 'there's a whole range of challenges, from systematic, community based, family based and all sorts' Kirk, UK. As with empathic approaches, there was a period of adjustment and trying to understand what was happening for the person with Alzheimer's: 'It was difficult to kind of in my

head, try and figure out that okay, you know, what is happening exactly?' Nomsa, South Africa.

Early coping in the caring role involved gathering information about the disease. Emily (US) was 'shocked' and 'afraid' at first because she knew very little about dementia but: 'typical of me, I wanted to find out everything about this because I thought that I could control it'. This included navigating the system to get social benefits and support, and setting personal boundaries to improve their ability to cope. Denise found an online Dementia Care model (Positive Approach to Care, teepasnow.com) in the US helpful in understanding each stage of Alzheimer's: '...like where mom is and... as it progresses, like what to expect and how to respond to her in these different, um, stages'.

An organising approach often included an assumption that the caregiver would be able to get whatever they needed to perform their role. This included getting medical advice from doctors or from colleagues or friends, practical caring advice from professional caregivers, and advice about the disease or about state benefits from charities and online sources. For example, Angelina's husband (a paramedic) taught her to do a basic health check (blood pressure, heart rate) which she found helped her be a better caregiver. Such information becomes a cornerstone of the caregiving role, filling gaps in knowledge

rather than emotional support (Table 3.3). Kirk used a picture of his laptop to talk about how he kept himself connected, even during COVID-19, to information, family, friends and whatever he needed to look after his mother and himself (Table 3.1).

Caring here was akin to a professional role, and there was frequently a sense of near self-sufficiency: 'I don't find it difficult...it's a fairly straightforward lifetime job' Curly, UK. Caregivers were likely to be 'proactive' (Table 3.4), and difficult situations were addressed through rational reflection, or through acceptance of the role and of their own limitations. When Rosa's mother was hospitalised because her glucose was high, Rosa reflected 'she's compulsive and I couldn't control that'. (Brazil). Their expertise was re-enforced and confirmed by others, or through their own sense of agency in relating to authorities (Table 3.5).

There were skills and time needed to manage the financial or legal side of caring: paying bills, setting up employment contracts for paid caregivers, applying for grants, or managing power of attorney were themes that especially came up in UK and US. Agnes had power of attorney over her father's finances, but also managed her own and her daughter's finances: 'It's, it's just like once a month I sit down with all these cheque books and go through, make sure everything's paid'. (US).

Caregivers with strong organising narratives generally seemed confident in their coping strategy. Angelina (UK), who had given end of life care to five elderly relatives, reflected on her general approach: 'I'm the type of person where, I don't take nonsense. I'm not a panicker, I'm not a stressor, suck it up and get on with it, you know?'. Nevertheless, there was always the uncertainty of having to adapt to a constantly changing and degenerative condition. Emily reflected on being aware of her own limitations and getting help (Table 3.6). Nomsa, who is a pâtissier and cake decorator in South Africa, makes an analogy between caring and making the perfect cake (Table 3.2). While the focus on organising and planning gave these caregivers a sense of expertise (as experts in care), some wanted medical professionals to provide reassurance and monitor their loved one's progress (Table 3.7).

3.2 | Non-Identifying and Reluctance Narratives

Some caregivers did not easily identify with the caregiving role and instead sought to maintain their pre-caring identities (e.g., as son/daughter, husband/wife). They could have a close connection with their loved ones or feel emotionally distant from them. However, the mismatch between wanting to maintain a pre-caring identity and the demands of caring created various kinds of conflicts and uncertainties.

3.2.1 | Non-Identifying Approach—'I do Everything I Can...There's Nobody Else'

Family members who did not readily identify themselves as caregivers often felt deeply committed to their loved ones but had little know-how or support in their caring role. For George,

taking care of his wife's needs was not so much a caregiver's duty as an extension of a long and happy marriage (Table 4.2). Mara, who worked full time remembers making a commitment to look after her mother, who is now in a home (Table 4.3). There was a gentle, sometimes playful and loving attention to their loved one's needs (Table 4.4). However, there was a yearning for their loved one to return to the person they were before Alzheimer's, appealing to their rationality or coaxing them to fall back on their old familiar roles (Table 4.5).

Family members with a non-identifying approach recognised their own lack of knowledge or expertise about Alzheimer's: 'I have no, no idea how you're supposed to deal with Alzheimer's...' George, UK. They also acknowledged their own unprocessed emotions: 'the only challenge I've got is accepting that it's happening', Tedcu, UK. Several non-identifying family members used pictures related to memories of unresolved emotional upset. Mara used a stock image of a wet chicken to describe difficult feelings and strong emotions she was processing such as anger and guilt (Table 4.6 and 4.7).

While there was a strong motivation to help their loved one ('I'm quite happy doing what I'm doing' Tedcu, UK), participants here could end up feeling they were doing so without necessary information or support. This led to feelings of aloneness and abandonment. George used a picture of his computer to talk about monitoring his mental health (Table 4.1). Tedcu felt strongly that there was a need for someone to guide him and check up on him and his wife: '...it would just be nice to know now and then that, somebody has your back, and I think that's missing at the moment'.


3.2.2 | Reluctance Narrative 'I Didn't Sign Up for This'

Family members with a Reluctant narrative lacked specialist caregiver knowledge and expertise like non-Identifiers and felt like they were struggling in isolation. Some were juggling multiple commitments, such as demanding jobs, looking after children and grandchildren, or managing their own mental health. Some were trying to care for a loved one at a distance.

Participants here gave a sense that their caring role had caught them out: 'this isn't temporary, this is every day...it sort of dawned on me that, oh God, I am actually, I am a carer now', Nasrine, UK. Or that they didn't have the credentials or the time to be a caregiver. Jane had a young family and full-time job and didn't have the time or capacity to be a caregiver (Table 5.3). She looked into employing private caregivers for her mother but felt she did not 'want to or have the capacity to do this...sort of contract work'. The relentless nature of the caring role meant participants could end up feeling resentful and trapped, as represented in their photographs. The benefits of the caring role were not immediately apparent to those with a reluctant narrative, 'there's no reward to Alzheimer's is there?' Charlie, UK (Table 5.4).

Emotional distance from the person with Alzheimer's, or a sense that this is no life for their loved one or for them was common: 'I was left alone with a person who cannot

TABLE 3 | Organising approach: Illustrative quotes and photographs.

1		<p>'Laptop...is my gateway to the world...it was the gateway to communication in terms of complaints and dealing with people. It's the gateway to social media, you know, I follow Twitter and Facebook and stuff. Um, gateway to WhatsApp and keeping in contact with me brother or carers who are part of a little group. Er, er, it's um, a godsend for...just being able to get things when I needed them. So, you know, when I needed incontinence pads, bang, ordered, delivered three days later. (...), so, basically, it's just, it's my conduit to, to, to looking after me mum and, also, looking after myself'. Kirk, UK</p>
2		<p>'So people might view the cake and say, yoh this thing is so beautiful, yoh what you are doing is beautiful. But, um, the process leading up to that it's filled with a lot of sometimes self-doubt. You know? And the self-doubt is because you... you... you are not sure if it's going to turn out the way that you intended to turn out. Um, it's also, it's...it's tricky. Baking is it's, it's scientific. So it's easy for things to flop, you know, and that probably speaks to a lot of my maybe emotional state. Because it... it's... it's... it... the there's difficult moments. You know, and I have to consciously pull myself out of those difficult moments'. Nomsa, South Africa</p>
3	<p>Curly, went on a 12 week course organised by a local charity with talks from medical professionals on how to handle medical situations, and public sector advice on support available for caregivers: 'I came back with a three inch thick file of very useful information. And that um, got me going on all the necessary places'. Curly, UK</p> <p>'I talk to her caregiver, because she has experience'. Laura, Brazil</p> <p>'Mr Google...Alzheimer's Society helped (...) Caregivers First and Caregivers UK'. Kirk, UK</p>	

(Continues)

TABLE 3 | (Continued)

4	'I suppose because of my proactive nature I found these, the things that I need, the day centre etc., I feel, I don't know, a little bit pleased with myself that I'm a bit, I don't want to say self-sufficient, I don't know what it is'. Sally, UK
5	'...my regular GPs, I've been with them for 20 years, so they, they, they know me, they know my caring abilities, they know my caring journey. So, if I ring and need help and it's one of them, then I get everything I ask for because they know me and they know that I'm only ringing because it's urgent'. Angelina, UK
6	'I was getting a little more um, inundated with the responsibilities for, my partner. And it was starting to wear on me. And this friend happened to be a retired Chaplin, for a hospice and she said, you might want to call hospice and see what they can do to help you'. Emily, US
7	'I went to the [local doctor] just recently with my mum because I was worried about her, her, her slowly moving her hands like this, they, they're now clenched and it's part of dementia, you know. And um, and he said, "Well, what do you want me to do?" So, I said, "I just want you to tell me I'm doing the right thing!" Kirk, UK

understand what you are saying' Vincente, Brazil. Some mentioned their loved one's behaviours making them feel uncomfortable, wearing them down or even making them feel threatened (Table 5.5 and 5.6). Family members could struggle to understand their loved one's actions which created further distance between them. Distance could be compounded by grief and confusion about what was happening to them and their loved ones. When Eloise's husband moved into a home, she felt very upset: 'I mean, this is the love of my life. I'm, I'm, you know...(crying), I felt very dedicated to him, and it was very challenging for me to give, give up the closeness that I felt with him'. Nasrine used an image from the internet of a scene of post war devastation to illustrate her sense of loss (Table 5.7).

There was a sense that participants had been left alone to care without any recognition that the caring role was not suited to them. Vincente noted that there should be better state support for caregivers, and not an assumption that everyone is capable of, or invested in, being a caregiver:

Not everyone is capable of it, willing to do it. Because this requires taking on a huge responsibility...regional Alzheimer's associations need to be more active in providing this support because the general public is completely unprepared.

Vincente, Brazil

4 | Discussion

Our analysis suggests a novel 'Role-Needs Framework', that potentially offers more inclusive support for caregivers. This approach moves beyond the previous coping-effectiveness framework, dominant in the wider literature, that relies on a dichotomous adaptive versus maladaptive coping discourse [32, 48, 62–64]. Using a cross-country sample including the Global North and South, and robust approach to analysis, we identified a framework with four distinct approaches to caring, each with unique support needs. This situates existing concepts of emotion-focused and problem-focused coping in a wider caregiver role framework, revealing two additional approaches to caring previously treated as 'dysfunctional' in the literature [45]. By re-imagining caregiving styles that are traditionally less

acknowledged as valid positions to be addressed in the caregiver support literature, our framework suggests more holistic foundation upon which support resources could be developed.

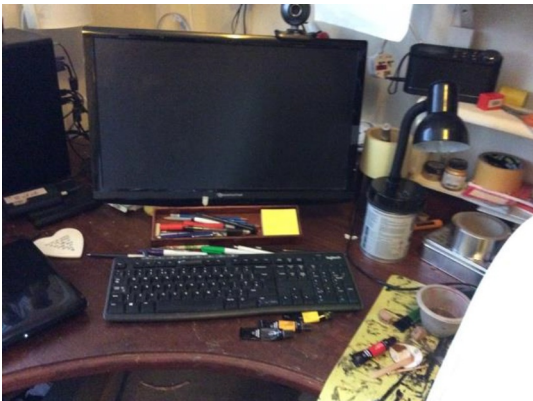

The importance of interventions to reduce caregiver burden are widely recognised [48, 63–65]. Yet they often focus on caregiver coping effectiveness, rather than on the suitability of caregiver support services [3, 66, 67]. Support typically offers advice and training to improve coping, but neglects those who do not engage with a caregiver identity. We seek to redress this imbalance by moving from a coping-effectiveness framework to a 'role-needs' framework. Caregiver willingness is becoming more recognised in the literature [68], however, this important issue is yet to be adequately incorporated into policy and practice. Stratifying how caregivers perceive their caring role, as we have done here, not only potentially recognises caregivers' diverse agency, but also has the potential to make caregiver support services more relatable and person-centred [69].

4.1 | Four Constructions of the Caring Role

We identified four approaches to caring: Empathising, Organising, Non-identifying with the caregiver role, and Reluctance. While current research recognises Empathising (emotion-focused) and Organising (problem-focused) coping strategies [48, 64, 70, 71], the two additional approaches to caring which we identify—Non-identifying and Reluctance—are side-stepped by the current coping-effectiveness approach [41].

Non-identification or reluctance to engage with the caregiver identity appears in the literature on coping as a failed or 'maladaptive' strategy of caring associated with avoidance type responses to the challenges of caring: self-distraction, venting, denial, giving up, and self-blame [45, 47]. In our study, we sought to re-imagine non-identification and reluctance from the caregiver's perspective, not as a poor or faulty strategy, but as common kinds of disengagement with a caregiver identity that are meaningful. While Non-identifying caregivers may have a strong loving relationship with the person with Alzheimer's, their caring duties are framed as an extension of pre-diagnosis relationship identities. They consider themselves to have little or no real understanding of the disease, nor how to manage it, and may have strong emotional responses relating to the life changes that have accompanied the disease

TABLE 4 | Non-identifying approach: Illustrative quotes and photographs.



1		<p>'I'm using the writing as a diary. It's not an accurate diary, my thoughts, my personal thoughts, what's happening inside my head. The other day I wrote down, I came in and I wrote this piece, only on my computer, it's not to anybody else, I wrote this piece. And I realised how black I was feeling, how low, how very, very low I was feeling'. George, UK</p>
2	<p>'We've been married quite a long time, in fact a very long time. And we love each other very much, you know, and it's as simple as that. And I want to do everything I can to care for her. Simple as that...there's nobody else'. George, UK</p>	
3	<p>'I made this commitment when she fell that day and we had to go to hospital, to myself; my mom is not going to go through this and Alzheimer's alone, I'll be there'. Mara, South Africa</p>	
4	<p>'we're not at the stage yet, although she constantly reminds me that it will come, (...) don't forget, she said, one day you're gonna have to take me to the toilet [Laughs heartily]'. Tedcu, UK</p>	
5	<p>'if we're going out, we can't really wear those trousers, can you? Because they're, they're really pyjamas'. George, UK '...there's a funny thing, she cannot make a decision, if I said, do you want a glass of red wine or do you want a glass of white wine? which is odd, not odd, it's um... because the thing we need, we've always done is to talk about things and she had strong ideas about this and about that'. George, UK</p>	
6	<p>'This is why I am angry all the time ...it's not just how to take care of that person. It is actually... witnessing somebody very intelligent, so functional, become nothing. So how do I cope with that?' Mara, South Africa</p>	
7		<p>'I have to juggle to my mom, leave my husband that's also elderly. Leave him at home and that is my water down chicken there, that explanation of the guilt that I've experienced. (...) I just felt guilty all the time'. Mara, South Africa</p>

progression. Having support in this context means having access to a professional with Alzheimer's expert knowledge, who has oversight over their loved one's care and health needs (e.g., guiding them in case of a crisis, telling them what to expect for each stage of the disease). These caregivers may be highly motivated to help but the lack of support is critical in their caregiver experience.

Reluctance also means having less specialist knowledge and expertise, and this approach may include finding little meaning in, or openly rejecting the caregiver identity. Family members with a reluctant narrative may have a sense of being forced into a role that they do not want, or which is just not possible for them. They find caring duties upsetting and draining. Whilst

juggling competing demands was also evident in other narratives (e.g., empathic), here it resulted in greater role conflict and increased caregiving burden. They may need professional support in coming to terms with their loved one's diagnosis and the life disruption it brings, but also for managing the day-to-day caring role. While Reluctance and Non-identifying caring approaches seek the best outcome for the person with Alzheimer's, family members in this position are not looking to grow their expertise as caregivers, and may not have the time, resources or inclination to care for and advocate for their loved one. While therapeutic support may be welcomed by some, getting external practical and professional support is likely to take priority. Since the 'caregiver' identity does not resonate with them, generic offerings such as caregiver training and 'information packs' are

TABLE 5 | Reluctance narrative: Illustrative quotes and photographs.

1		<p>'I felt like I'm constantly cleaning her and I'm constantly cleaning...you know...And I, you know, I don't like saying this, but I actually felt quite resentful that I was doing that. I didn't want to do that, and I didn't sign up for that'. Nasrine, UK</p>
2		<p>Jane describes in detail the challenges of living far away and depending on paid carers, who did not do a good job, to look after her mother</p> <p>'I was shocked and angry, (laughs) um, with the state of the kitchen, hence the photo'</p>
3	<p>'there's an awful lot of the hands-on stuff that the carers, you know, obviously have had to do on a regular basis, which I couldn't do. Um, I couldn't do because of the distance, and I couldn't do because I, I don't feel it would have been my strength either'. Jane, UK</p>	
4	<p>'...it's not very easy to talk to a person with Alzheimer's, it's not very easy to live with a person with Alzheimer's. And the journey is not at all romantic.' Antonio, Brazil</p>	
5	<p>'try...not to be irritated, or, um, take to heart, um, when he keeps repeating and, and he won't just let me be to read a book or he, he takes all my attention...consumes my life'. Sarah, US</p>	
6	<p>'He was challenging to take care of because he would fight you. And this is one of the reasons that he is now in a home. It was just becoming too difficult, uh, unsafe for me'. Eloise, US</p>	
7	<p>'I also put a picture of devastation because I felt devastated, as a person both seeing my mum... or, "losing" my mum completely like she's disappearing almost in front of me as time—it was happening gradually but she's disappearing'. Nasrine, UK</p>	

less likely to meet their needs and may even promote shame and stigma.

Our study also provides a deeper insight into the context in which emotion-focused and problem-focused coping strategies are played out in the caregiver role. Building a sense of expertise is key to both empathising and organising approaches to caregiving. Previous research suggests that both approaches are associated with lower burden and perceived stress [71, 72]. For Empathic caregivers the relationship with the person with Alzheimer's provides a central focus for understanding and growing expertise within the caring role. The development of emotional skills such as patience, compassion, and co-regulation not only improves the quality of life of the person with Alzheimer's, but contributes to a

strong sense of personal growth for the caregiver. This may explain why the broader literature [73, 74] suggests that emotion-focused approaches are associated with better caregiver outcomes over time. Our study builds on existing literature on the importance of therapeutic interventions to support emotion-focused caring [63], and suggests that Empathic caregivers need time-relevant information. This means getting help and support from professional therapists, peers and trusted family and friends and ongoing, practical information that builds their sense of understanding and expertise.

Previous research shows that those using problem-focused coping strategies tend towards taking active steps to change the challenging situation, including planning, and seeking help

or advice from others [15, 74]. Organising caregivers take a structured approach to caring and value external information and resources, and want to have an overview of the support available from the outset. Caregivers who value this approach are likely to have existing skills related to managing difficult tasks and look to the world around them for solutions to the problems that arise. Since they are keen to develop their expertise around caring, they are likely to welcome training, structured information, professional information, and advice that builds upon their existing skills. While their expertise grows, they have an acute sense of their own limitations and welcome professional guidance to help them navigate challenges as they emerge. Caregivers who take Empathic and Organising approaches may also value sharing their considerable expertise and experiences to help others.

4.2 | Implications for Practice and Policy

Each of these approaches to caring (empathic, organising, non-identifying and reluctance) helps to distinguish key differences in the *primary* lens through which the family member sees their role in relation to the person with Alzheimer's. This framework is supported by evidence in the wider literature that not all family members have the time, resources or motivation to be caregivers [68]. Stratifying support to acknowledge all these approaches, as suggested here, promotes equality to a broader spectrum of experiences by recognising different ways in which family members may position themselves in relation to their caring role. Our framework is beginning to open up discussions around the validity of different approaches to caregiving to reduce stigma and develop ways of tailoring support. This is relevant to the health policy and charitable sector, evidenced by our partnership with FEBRAZ (the federation of national Alzheimer associations) in Brazil where, using insights from our research, we have worked with patient advocates and stakeholders to create a visual tool for national charities and policy makers to increase awareness and understanding (<https://febraz.org.br/retratos-do-cuidado/>).

Impact is also evident in the UK where, in partnership with national charities, we are currently designing and testing a questionnaire using our framework to enable organisations to better identify caregiver needs, during the caregiver assessment and subsequent support planning. More directly, discussions with individual caregivers suggest that recognising these different approaches to caregiving may also ease tension between family members by increasing understanding of each other's caregiving style. This perspective is useful to inform future caregiver guidance, which is typically written from the perspective of ideal type ('good' coping) behaviours and responses from caregivers. While these are good standards to set in a professional care setting, as we see here, they fail to reflect the experiences and needs of many caregivers.

4.3 | Strengths and Limitations

Our multi-country qualitative study provides a novel way to understand the support needs of caregivers, and we engaged

stakeholders at every step. The use of photo-elicitation enabled participants to situate their lived experiences within the context of their everyday lives, whilst also deepening stakeholder understanding and engagement [75] resulting in translation into guidance.

The four types of caregiver experience represented here, are intended to illustrate predominant ways of caregiving that we found in our data, and which help to better understand and tailor caregiver needs. However, we are not suggesting that these are either conclusive (the only approaches to caregiving) or exclusive (each caregiver fits into one approach) and caregivers may identify themselves in more than one of these types. Caregiver needs, which are rarely linear, may require different approaches at different times [4, 76]. However, some caregivers will fit well into these individual approaches and our framework fills a gap in the current support provision by acknowledging and validating a fuller spectrum of caregiver experiences, including those who do not associate with the term 'caregiver'.

While our study draws on interviews with caregivers in four countries, whole study online working (from recruitment to participation) in resource-constrained settings has unique challenges [77], which was particularly evident in South Africa despite working with local organisations and researchers. We also acknowledge that further research is needed to test out the inter-cultural prevalence of these types. The literature suggests that culture plays a part in the way caregivers construct their role [64, 78], but this in itself is complex and nuanced [39, 64, 79–83]. While service providers should be aware of potential cultural beliefs relating to support seeking, for example shame [43], we believe our four approaches contribute a constructive basis for discussing barriers and facilitators to support. Based on the 34 interviews we carried out, there were particularly strong examples of Organising approaches in the UK and of Empathic approaches in Brazil. However, examples of Empathic-type emotion-focused and Organiser-type problem-focused coping in the context of caring for a person with Alzheimer's are prevalent across cultures [83, 84]. Further research may help to understand potential variations between caregivers in different countries. We have not addressed here how culture may act as a mediator in access to support amongst minority cultural communities [39, 85, 86]. Stigma and cultural expectations of familial support may also mean that caregivers who take a Non-Identifying or Reluctant approach are less likely to identify openly. These are important additional considerations that need to be addressed as discussed above.

There was no evidence that these four approaches to caregiving are gendered or represent stages in the caring journey. We found caregivers who had been caring for as little as 1 year or as long as 7–9 years in each approach. However, further research is needed to better understand the factors that contribute to adoption of different approaches to caregiving and whether people transition between them.

5 | Conclusion

This robust cross-country study, incorporating innovative visual methods, seeks to shift the debate to more realistically assess

diverse caregiver needs and assist with making existing support provision more user-informed and relatable at the point of offering. Our findings help to show that exploring support needs from the perspective of how caregivers see their 'role' can be an important way forward in planning and implementing support packages and training for policy makers and third sector organisations to offer more user-guided, tailored, and timely assistance. Incorporating our new framework of 'role-needs' into the language used by charities and policy makers could help to reveal and support a wider range of caring approaches, helping people identify their own experiences within caregiver support. Providing recognition of caregiver styles in this way, means that caregivers may be more likely to engage, come forward for help and receive the right kind of support to suit their circumstances.

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Conflicts of Interest

Tina Cartwright, Damien Ridge and Catherine Loveday have received research funding (via their institution) from Roche for this study. Fauzia Knight was employed for the current project through funding provided by Roche to the University of Westminster. In her role as Head of Research at ADI, Wendy Weidner provides an occasional advisory role for industry, for which she receives no personal remuneration. Jannice Roeser is an employee of and shareholder in F. Hoffmann-La Roche. Candida Halton is a director at Studio Health which has received consultancy fees from Pfizer, Roche, Takeda, MSD, and AstraZeneca.

Data Availability Statement

The data supporting the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.