

Emotion work and feeling rules: Coping strategies of family caregivers of people with end stage dementia in Israel—A qualitative study

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Inbal Halevi Hochwald 

Department of health systems management, Ariel University, Ariel, Israel;
School of Nursing, Max Stern Yezreel Valley College, Israel

Daniella Arieli

School of Nursing, Max Stern Yezreel Valley, Israel; Department of
Sociology and Anthropology, Max Stern Yezreel Valley College, Israel

Zorian Radomyslsky

Department of health systems management, Ariel University, Ariel, Israel;
Maccabi Healthcare Services, Tel-Aviv, Israel

Yehuda Danon and Rachel Nissanholtz-Gannot

Department of health systems management, Ariel University, Ariel, Israel

Abstract

Background: End stage dementia is an inevitable phase following a prolonged deterioration. Family caregivers for people with end stage dementia who live in their home can experience an emotional burden. Emotion work and “feeling-rules” refers to socially shared norms and self-management of feelings, as well as projecting emotions appropriate for the situation, aiming at achieving a positive environment as a resource for supporting others’ wellbeing.

Objectives: Exploring and describing the experience of family caregivers of people with end stage dementia at home, in Israel, unpacking their emotional coping and the emotional-strategies they use, and placing family caregivers’ emotion work in a cultural context.

Method: We conducted fifty qualitative interviews using semi structured interviews analyzed through a thematic content analysis approach.

Corresponding author:

Inbal Halevi Hochwald, The Max Stern Yezreel Valley Academic College (YVC), Afula - Emek Yezreel 19300, Israel.
Email: inbalh@yvc.ac.il

Findings: Four characteristics of emotion work were identified: (1) sliding between detachment and engagement, (2) separating the person from their condition (3), adoption of caregiving as a social role and a type of social reinforcement, and (4) using the caregiving role in coping with loneliness and emptiness. The emotional coping strategies are culturally contextualized, since they are influenced by the participants' cultural background.

Discussion: This article's focus is transparent family caregivers' emotion work, a topic which has rarely been discussed in the literature is the context of caring for a family member with dementia at home. In our study, emotion work appears as a twofold concept: the emotion work by itself contributed to the burden, since family caregivers' burden experience can evolve from the dissonance between their "true" feelings of anger and frustration and their expected "acceptable" feelings ("feeling-rules") formed by cultural norms. However, emotion work was also a major source of coping and finding strength and self-meaning. Understanding and recognizing the emotion work and the cultural and religious influence in this coping mechanism can help professionals who treat people with end stage dementia to better support family-caregivers.

Keywords

end stage dementia, end of life care, family caregivers, emotion work, feeling-rules, qualitative study, cultural background

Introduction

Dementia is characterized by prolonged deterioration, during which person with dementia loses their mental, cognitive, and motor abilities (Livingston et al., 2020). At the end stage of the disease the person loses the ability to speak, smile, or move (Bužgová et al., 2017; Sampson et al., 2018). Eventually, aspiration pneumonia, pressure ulcers, and urinary tract infections shorten their life expectancy (Schmidt et al., 2018; Van Der Steen et al., 2011).

Worldwide, most people with dementia live in the community and are cared by family caregivers (e.g., spouse and/or adult children) (Brodsky et al., 2013; Van der Lee et al., 2017). Caring includes personal and instrumental assistance with daily activities (e.g., bathing, dressing, shopping, and housework) (Schulz et al., 1995). The involvement of family caregivers with care providing, decision making and the responsibility for quality of care and its results increases in accordance to the level of disability (Van der Lee et al., 2017).

Caregivers reported having gained from caregiving by personal and spiritual growth, and by improvement in their relationship with the care recipient and with others in the family (Netto et al., 2009). Yet, in addition to the gains, the family caregivers reported a sense of burden. Burden is one of the main common terms used to explain how much emotional, social, economic, physical, health, and spiritual conditions are subjectively affected and made worse for family caregivers when caring for people with end stage dementia (Hemingway et al., 2016; Sternberg et al., 2019; Zarit et al., 1980). Burden affects not only the family caregivers' health and quality of life, but also the quality of care they provide (Campbell et al., 2008; Halevi Hochwald et al., 2021).

When caring for a family member with dementia, culture (including ethnicity) plays an important role regarding caregivers' burden their coping processes and their expectations for social support, as well as the expectations of society towards them (Elnasseh et al., 2016; Richardson et al., 2019). Different cultures present a variety of cultural values and beliefs regarding dementia and care of older people (Ayalon, 2018; Chiao et al., 2015; Leichtentritt et al., 2004).

Emphasizing the cultural influence on one's emotional burden draws attention to a unique aspect of emotion work that culture dictates. Changing one's inner feelings and their outward expression to meet social guidelines was referred to by Hochschild (1979) as conforming to "feeling rules." The attempt to manage the often experienced dissonance between the family caregivers' "true" feelings and their expectations from themselves and from others, and present an energetic and enthusiastic performance, was termed "emotion work" (Gray, 2009; Hochschild, 1979, 2012).

Emotion work has two main meanings: the first refers to *self*-management of emotions, so that the self can experience (and project outwards) emotions that are appropriate for the situation (Hochschild, 1979). The second meaning is adopting and embracing a positive attitude when providing care and support to *others*, specifically during day to day interactions with people with dementia (Herron et al., 2019; Hochschild, 2012). The emotion work can result in a dissonance when family caregivers have to suppress their true feelings and control their frustration in order to behave in the way they perceive to be appropriate (Herron et al., 2019).

Feeling rules were mostly described regarding professional formal caregivers, and referred to social conventions regarding the accepted extent, direction and duration of feelings (Delgado et al., 2017; Lopez, 2006; Michael, 2015). Given that social conventions and feeling rules exist at all levels of social interaction, emotion work is something in which individuals constantly and privately engage in various ways (Simpson & Acton, 2013). In the case of caregiving for people with dementia, the feeling rules include putting the needs of the person with dementia before the needs of the caregiver, protecting him/her, and avoiding conflict and arguing as the "right way" to respond (Herron et al., 2019).

Numerous studies have dealt with family caregivers' burden (Hemingway et al., 2016; Kjällman Alm et al., 2013; Zwerling et al., 2016), and with the emotion work of professional formal caregivers and institutional staff members (Bailey et al., 2015; Brighton et al., 2019). This paper wishes to apply the concept of emotion work to the case of family caregivers, as their role is similar regarding length of care, burn out and emotional exhaustion (Herron et al., 2019; Vandrevale et al., 2017; Wilkinson & Wilkinson, 2020). There has been very little discussion regarding family caregivers' burden using terms of emotion work, although the use of this concept may clarify family caregivers' complex role. Nevertheless, the emotional distress of family caregivers differs from that of professional staff members as it has extra layers of emotional intricacy, intensifying their emotional distress. An example of that emotional intricacy can be seen in the identity discrepancy during family role changes, that is, when giving up one's role as the child of a parent or as a spouse, and taking on a new role (Montgomery et al., 2011). Little is known about family caregivers' emotion work when caring for people with end stage dementia living at home.

While the emotion work of professional service providers is shaped by the professional culture, the emotion work of family members is shaped by the community's cultural norms. Therefore, the objective of this study is twofold: (a) to unpack family caregivers' emotional coping and the emotional-strategies they use; and (b) to place family caregivers' emotion work within the appropriate Israeli cultural context.

Methods

Design

A descriptive qualitative phenomenological study was carried out, using semi structured interviews analyzed through a thematic content analysis approach (DiCicco Bloom & Crabtree, 2006).

Participants and recruitment

The study included 50 Israeli family caregivers (mostly spouses and adult children), who had been caring for 50 family members (people with end stage dementia) in the past year. Participants were recruited based on a list and information provided by professional staff members working in two community services frames of care specializing in caring for end stage patients (home hospice units and home care units) (Halevi Hochwald et al., 2020). The inclusion criteria were all patients were mostly living at home during the past 6 months; they were in the end stage dementia (FAST (Functional Assessment Staging Test) $\geq 7c$ they had lost the ability to speak or smile and move without considerable assistance); they had incontinence and needed help in all day to day functions (Reisberg, 1988); and had at least one more risk factor for a poor prognosis hospitalization at least once during the past 6 months, had at least 10% of weight lost, and/or had a urinary tract infection and/or pneumonia and/or pressure ulcers at least once (Aworinde et al., 2018; Mitchell et al., 2010; Van Der Steen et al., 2014). Exclusion criteria included: family caregivers who cared for patients with a longer than 6 months prognosis, and family caregivers who cared for terminal patients resulting from other sever health conditions (i.e., cancer, end stage heart failure). Participants were mostly female secular Jews, living and working close to Israel's central area. The average age was 62 years (min. 24, max. 92) (Table 1). In 98% of the cases in the study, the person with dementia had a homecare worker (90% had a live in migrant home care worker and 8% had a live out Israeli home care worker).

Table 1. Characteristics of family caregivers.

	Family caregivers (n=50) *
<i>Gender</i>	
Male	19 (38)
Female	31 (62)
<i>Family relationship with people with end stage dementia</i>	
Spouse	15 (30)
Son/daughter	34 (68)
Other	1 (2)
<i>Religion</i>	
Jews	41 (82)
Muslims	8 (16)
Christians	1 (2)
<i>Place of birth</i>	
Israel	29 (58)
Other	21 (42)
<i>Family caregiver</i>	
Secular Jews	26 (52)
Religious Jews	15 (30)
Ultra-orthodox Jews	3 (6)
Religious Arabs	6 (13)
<i>Residence</i>	
Tel-Aviv metropolitan area **	27 (54)
Outside of Tel-Aviv metropolitan area	23 (46)

* Data presented as n (%); ** Central Israel

Data collection and analysis

Fifty semi structured in depth individual interviews, during one episode of fieldwork, were recorded using a digital recording device and subsequently transcribed (Botes, 1996). All interviews were carried out following an explanation of the research goals and conducted according to a semi structured topic guide: The first part of the interview included closed ended socio demographic questions, and the second open ended questions dealing with the research topics which had been selected based on former research conducted both in Israel and worldwide (Peacock, 2013; Simpson & Acton, 2013; Smith Carrier et al., 2018; Sternberg et al., 2019), as well as adjustments made following a short pre study conducted with five interviewees for validation purposes. Prompts included the participants' experiences, challenges, and decision making processes when caring for people with end stage dementia, as well as their concerns and planning for end of life care at home. Additional questions emerging from each dialogue between interviewer and interviewee were added if and when necessary, in an inductive, structured and evolving process (Corbin & Strauss, 2014; DiCicco Bloom & Crabtree, 2006). A written informed consent document was signed by the family caregiver prior to the interview. The study was approved by the local Ethics Committee and adhered to the tenets of the institutional review board, based on the Helsinki-Declaration of 1975 (BBL00118-17).

This study used an inductive content analysis process. The aim of this research strategy was not to test theoretically preconceived hypotheses, but rather to identify emergent and underlying themes in interviewees' experiences, as a means of facilitating both theoretical development and practical understanding (Graneheim & Lundman, 2004). Accordingly, we performed a thematic approach analysis (Tong et al., 2007) by three independent researchers who reviewed the transcripts (IHH, DA and RNG), in order to ensure the trustworthiness of the themes (Patton, 2002). Regular meetings were held among the researchers to discuss any issues raised during the analysis process.

The data analysis consisted of four main stages: The first reading indicated that the interviewees described themselves as performing emotional work of various types and meanings. The second reading was therefore focused on locating the main issues that called for emotional work and identifying the main strategies of the emotional work the interviewees were doing. The next stage was developing each of the issues and meanings as a theme. This stage included forming higher level conceptual themes which were verified and refined as the analysis proceeded (Chakraborty & Su, 2017). Issues, meanings, and strategies were considered to be themes when they appeared in more than 80% of the transcripts. In the fourth stage of analysis, each category and interpretive claim were repeatedly checked and developed through a re scanning of the transcripts in search of examples, exceptions, variety, and nuance. The data analysis eventually led to a point where no new themes emerged (Saunders et al., 2018). In accordance with the theoretical underpinnings of inductive content analysis, and in order to allow the reader to assess the trustworthiness of the analysis, each interpretive statement will be accompanied by an illustrative verbatim quote. The findings were summarized alongside existing theory and literature, demonstrating whether the information had complemented or supplemented existing knowledge. In order to ensure anonymity, participants' identifying details have been concealed and only pseudonyms used.

Findings

"Emotional coping strategies" recurred in all interviews. The ways interviewees chose to narrate their experiences, the expressions, and terms they used to describe what they are doing and how they are coping with the situation, all indicated the centrality of emotion work in their role as family

caregivers. Interestingly, we also found that interviewees' choices of emotional coping strategies, were impacted by their cultural background. Four main themes associated with emotion work were identified: (1) sliding between detachment and engagement, (2) separating the person from their condition, (3) adoption of caregiving as a social role and as way of social reinforcement, and (4) using the caregiving role in coping with loneliness and emptiness.

Sliding between detachment and engagement

Most interviewees' descriptions expressed movement between detachment and engagement: availability and accessibility to serve the needs of the person with dementia on the one hand, and on the other acknowledging their own need to stay separate and protect themselves from actions that may hurt them or flood them emotionally. This back and forth movement was used as a coping strategy to provide care under the burden caused by the intensity of demands.

Talia (age 57, married +1, secular Jewish woman), caring for her mother, described:

We (Talya and her brother) are involved in every decision, but we do not give personal care. If I must change her diaper, I will, but it is not my responsibility, it is not for me to change her bed, it is not good for me and it is not good for her. The relationship is too hard anyway... I touch her a lot because I think it is important communication, but I do not do it with pleasure, I do it for her.

Talia described her deep commitment and engagement, but at the same time her description revealed her attempt to stay emotionally detached. She touched her mother, but this touch was presented as a therapeutic act rather than a personal, emotional expression. She described herself as deeply involved, but at the same time defined the limits and boundaries of her involvement. Her commitment to her mother stemmed from a feeling of internal moral motivation rather than a bond of love.

My commitment is devotion and obligation, not a place of love. I have total responsibility for her and her 'wellbeing' as I understand it.

A common notable mechanism for detachment was describing the caring process as a "project," using rationalistic terms. An example for this mechanism was described by Amos (age 46, married+3, secular Jewish man), caring for his father, when addressing this caring as a job that needed to be done. He referred to the relationship with his father using the past tense and objectification (e.g., it, object, and empty shell). Nevertheless, there was longing and commitment:

There is something in this disease that **it** becomes an **object** that needs to be treated. It becomes an **event** that needs to be dealt with forms, procedures. You do not think about **who** you are dealing with anymore but **what** you are dealing with. It is very difficult (sobbing).

Amos described the complicated emotional experience towards his father's long deterioration, but also the tension between him and other family members, especially around decision making for his father's wellbeing. This tension aroused in him a desire to disconnect emotionally and objectify his relationship with his father:

I will feel relieved when it's over. It is an egocentric thought, but it exists. It will ease this terrible tension between me, my sisters, and his wife. He is in a crappy situation He is becoming a shell... he is dead and not dead.

Another common mechanism of detachment was scheduling one's involvement. Dana (age 52, married+4, secular Jewish woman), caring for her mother, declared several times during the interview that she was protecting herself by the emotional disconnection she had constructed through use of a strict schedule, as this was a workplace and not a family visit. In this case, distancing oneself and using task oriented rhetoric to describe the relationship was her way of coping with vulnerability and frustration. She was in tears throughout the interview:

I have no patience for both my parents, but I do not show it. I am very professional. When I get into their home, I look at my watch and I tell myself that I'm going to be here for an hour and a half. Fifteen minutes before it's time to leave I tell my dad I have to go so he can get my full attention. it's like I'm getting paid for the time there. I'm very professional... I will not burst.... But when I am back in my car, alone, I can say it out loud, I do not have any more energy for you! As if I were saying that to them But I kept it in during the visit. I feel guilty because it's not their fault and I can't blame them for this situation, they didn't choose it... I love them but it's too much, I don't like this intimacy with them...(crying).

The mixed emotions involved in the caring, the combination and transitions between detachment and engagement and their consequences, were illustrated in the following description. Dana described her mother's severe deterioration which took place when she was on vacation. Despite the emotional storm she and her family went through, within a few minutes she overcame it and changed it into an emotional disconnection:

I went to put on my bathing suit and the phone rang. I heard the aid screaming – “mother! mother!” my mother wasn't breathing, and they called an intensive care ambulance. I called back and shouted, “cancel the ambulance! send it back!” I was horrified that they are going to resuscitate her or connect her to tubes, I wanted her to die. Eventually she started breathing again and they canceled the ambulance. I took my bathrobe then, and told my husband “Are you coming to the pool?” I found myself swimming in the pool and telling myself “are you crazy? What was just happening here? it's not normal.”

Separating the person from their condition: “It is the dementia and not my husband.”

A similar, yet different, form of emotional coping strategy was creating a separation between the person and their condition, as described by many interviewees. This allows the caretaker to experience contradictory emotions—resentment towards the condition yet a connection with and compassion towards the person. An example for this separation was mentioned by Yael. Yael (age 56, married+2, religious Jewish woman), is married to David who became sick with frontotemporal dementia 7 years ago. Yael described a violent relationship during the first few years. Yael's emotion work included redefining the relationship with her husband as a care relationship rather than a love partnership in order to readjust her expectations, hopes and disappointments. She described a struggle against anger and frustration by transferring anger from the person to the disease.

I do not care if he recognizes me or not, because the connection between us has changed. Today there is no partnership and I only care if he is in a good mood or if he smiles. I care for him in order to be able to look at myself in the mirror in the future. We are still connected by our past and our children, but I can't talk about love. It's mostly sadness, hardly ever anger, especially at him. It's not him, it's the disease. It is not his fault. I separate the two things.

Shira (age60, married+3, secular Jewish woman), divorced Nathan after a violent relationship prior to his being diagnosed with dementia. At the time of the interview, Nathan lived few minutes' drive

from her home in a rented home and was taken care by a migrant care worker. Despite the divorce, Shira saw herself and functioned as a main family caregiver. She visits Nathan daily and explained that she does it out of commitment to their mutual past and the person he was before the disease. She described her mixed feelings towards him and her efforts to manage those feelings in order to succeed in caring for him:

Occasionally, I get into my car and cry for an hour and only then I can drive home. I remember how he was, how I knew him in the past and what has become of him today. I feel my body is in terrible pain, but I tell myself hold it together, I don't have the privilege to drown, and I can't be angry with him. It's like cancer. Is it anyone's fault to have cancer? It is not his fault. I cannot get into the position of being angry with him.

Shira expressed the emotion work she had to invest in separating her negative feelings for the disease that led her to a divorce and the need to embrace a positive attitude when providing care to the person she had known in the past. She described the exhaustion and physical pain evolving from this coping mechanism.

Adoption of a social role as social reinforcement

The role of a caregiver, being morally obligated and responsible for the family member, was described in the majority of the interviews not only as a source of meaning but also as part of the identity and self-worth of the family caregivers within the family. The familial background and culture influenced the perception of the caregiver role.

Fatma (age47, divorced+4, religious Muslim Arab woman) was invited, after she divorced her violent husband, to live in her older brother's home and be the sole caregiver for her mother with dementia. Fatma expressed a high satisfaction with the duty of care and saw this role as the center of her life. She felt she had special knowledge and skills:

The nurse taught me everything, I do the same as she does. How to change bandages, how to care for her wound. Before that, I didn't know anything, but now, I'm like the nurse, like the doctor. It's good for me, it's fun, believe me when I tell you so, I care for her like for a little child, it's fun.

Fatma mentioned that she felt that she and siblings were part of the same group mission. However, she had the role of showing the way and had the knowledge and abilities to care for their mother. Despite that, she mentioned that she was under her older brother's supervision:

All of us fight for her life, the same as me, we love her like crazy. But if I forgot to do something for my mother, if I forgot to feed her, my brother will go crazy why didn't she eat, why didn't you do this or that... and how will it make me feel? Terrible, I could not look up to see his face.

Fatma and other interviewees mentioned that caring for old and sick people in the community was part of creating a legacy for the young generation through observation and imitation.

Whatever I do for my mother, my children will do for me. They watch me, how I care for their grandmother. In this way they learn to be loving and compassionate.

Muhammad (age 58, married +3, a Muslim Arab man describing himself as being a traditional but not religious), described the caring process of his mother as a source for family consolidation, keeping the family together:

It is good for us that mom is here and alive. My sister comes over from another village to care for her, I didn't see my sister in the past, today I see her once a week. Mother is like the glue that holds us together. Last year I brought a Filipino nurse to care for mom, but I saw everybody trusted her and went away, like in a hospital, so I have sent her away... today it's just us, we care for her in shifts. It is not hard, it's fun.

During the interaction between the interviewee and interviewer, some of the Jewish Orthodox and Arab Muslim participants presented their collectivistic culture as "we," with common norms and expectations, in comparison to "you," as referred to "others," the individual, secular people represented by the interviewer (IHH).

Fatma: I will not throw my mother into a nursing home. It is for people who have no families. If there is a family, why put them there? **We** do not do that, as opposed to what **you** do [referring to me the secular Jewish interviewer].

Tova (age 56, married +10, Orthodox Jewish woman) left her High Tech job a few years ago to take care of her dying grandmother. Tova is now caring for her mother in law in her home, without any assistance. She explained that her devotion and care were part of the cultural norms.

Of course, in the Orthodox population we care more for our parents. There is no doubt about it... **For us**, it is a matter of ideology, of respect to our parents, it's a 'Mitzvah' (Hebrew for 'religious commandment').

Tova also explained that fulfilling the role of the caregiver provided her with symbolic rewards, such as appreciation from the family:

If there was no appreciation, I don't know what I would do. And it's important, even when you tell yourself it isn't, that I do it for ideology. Eventually, we need the feedback... I'm not embarrassed about it... I know it's not humble, but okay, it's like refueling my engine (laughing with embarrassment).

Tova added that carrying out the caring practice was a source of self-value for her. It grants her a feeling of self-achievement and fulfillment:

I feel that I am in a stronger and higher spiritual place. Without this experience I would not have reached it... I'm sure I am in a higher spiritual place than millions of women out there that have careers.

Caring for a family member at home, as an expression of conforming to a community tradition, was also described by Igor (age 54, married +2, religious Jewish man). When his mother became severely sick with dementia, his sister collapsed under the burden of care and intended to transfer the mother to a nursing home, despite the cultural expectation that the daughter should care for the parents. Igor took over the role of caring instead. He felt special for his unique abilities in dealing with complicated situations and keeping the family traditions:

I would never take her to a nursing home. God forbid ... I told my sister that if she takes her to a nursing home, she (the sister) is like dead to me. It is like killing her. I constantly feel the responsibility of caring for her. Like she did for her parents and like her parents did for their parents before ... and thanks God, blessed be He, He has given me the ability.

In the case of Jamila (age 44, single+0, religious Muslim Arab woman), taking this role of a family caregiver was even presented as a way of compensation for failing in conforming to other social roles and/or cultural expectations, such as getting married and having children:

My family is always happy that I am here, and I am good for my mother. They say it is good that I am with her, since I didn't get married. I sleep next to her, in my parents' bed (her father died few years ago). It is good for me that I can hear her breathe during the night. I can't sleep alone. But sometimes I think that a woman my age needs to sleep in her own bed, no?

Using the caregiving role as a means of coping with loneliness and emptiness

Many of the interviewees described the fear of loneliness and emptiness they would feel once the person they were taking care of dies as worse than the burden of caring and keeping their family member alive. Therefore, the caring itself is meaningful and serves their need for company and meaning. It is important to note that this was found more strongly with interviewees who come from traditional communities—religious Jews and Arabs.

An example of this is Ibrahim, (age 87, married+3, secular Christian Arab), living in the same building as his 86 years old wife with dementia, his married son and his wife's migrant care worker. He described his fears of staying alone in an empty house:

Dying is the easiest thing. But if she dies, I will be left alone. It's hard for me (crying). We are old, we do not even hold hands anymore, but being left alone is hard, it makes me sad. Sometimes I think that if I had a gun, I would kill her and myself. It's hard for her and it's hard for me too.

Despite the struggle with caregiving and the absence of communication with his wife, Ibrahim was more anxious about loneliness, to a point that he did not separate his life and hers.

Yehuda (age 78, married+1, secular Jewish man), also described his sick wife and his efforts to care for her as a source of meaning for him:

You must understand, if she closes her eyes, my life does not count anymore. That is why I am fighting to keep her alive. If she is here, I am alive. And I know I will be fine with all the assistance around me, it's not that at all, but I will have no reason to be alive.

Igor (religious Jewish man, mentioned previously), an immigrant of Caucasian origin (an area that was part of former Soviet Union), described a close relationship with his mother with dementia, and fears of separation. The responsibility for fulfilling the task filled him with motivation and meaning:

Before, I was like an empty truck, jumping from every stone on the road. But now, with the heavy load, the truck is not jumping. There is a balance. So, I do feel tired but I'm in motion.

Yitzhak (age 74, married+3, Orthodox Jewish man), lives with his wife with dementia in a one-bedroom apartment. His daughter, a single parent, lives in the same building. Due to their limited

financial resources they both cared for the sick mother with no hired help. Both father and daughter found great significance and self-fulfillment following their mission. Yitzhak described their relationship as a sacred value, to a point of defining it as the only reason to keep on living:

I am going to take care of her as long as I live... This is our destiny and with God's help we will die together on the same day or the same week. This is my biggest fear staying alone after her.

Discussion

The theory on emotion work and feeling rules was originally developed to describe how service providers (e.g., flight attendants, nurses, promoters, and public workers) should manage an external expression of feeling through surface acting, termed emotion work, and using "feeling rules" as what "ought" to be felt as compared to what the "true" feelings were, when they provided service.

Professional service providers are required to maintain services and need to do emotion work in order to comply with expected emotion rules. Emotion work is described in the literature as an additional burden to their professional requirement, which is transparent, unrewarded and unrecognized labor (Herron et al., 2019; Hochschild, 1979). Paid care workers manage their emotions in order to ensure patient satisfaction and comply with organizational norms, often at the expense of their own wellbeing (Franzosa et al., 2019). Such strategies may be impractical for family caregivers, due to their relationship with the person with dementia, the environment and the external support available (Herron et al., 2019). Family caring is "hidden" in the home and therefore "transparent" and unrecognized (Lilly et al., 2012).

Family caregivers express feelings of frustration, anger and resentment, and describe putting on a positive attitude, putting the person with dementia first and protecting them as the "right way" to respond to these feelings (Herron et al., 2019). Caregivers are aware of feeling rules and experienced stress when they were unable to comply with them (Simpson & Acton, 2013). We found that these theoretical concepts are useful for in depth understanding of caregivers' coping strategies. In our study we adopted and conceptualized the terms "emotion work" and "feeling rules." Although some studies acknowledge that emotion work is a part of caring for a person with dementia (Herron et al., 2019; Simpson & Acton, 2013), they fall short of understanding the broad range of contexts, culture, forces and situations influencing caregivers' interpretations of feeling rules and their resulting emotion work, especially in the prolonged end stage of dementia.

Emotional work as a coping strategy with the burden of care was a dominant theme among most of the interviewees. In this study, we found that individuals exhibited a wide variety of emotion work expressions under the umbrella of this theme. We described four aspects of the emotion work family caregivers perform in order to provide the expected productive and patient centered caring. The first was sliding between engagement and detachment. We showed that interviewees developed a detachment in order to maintain engaged in their duties. The second focused on separating the person from their health condition, that is, regarding the disease as distinguished from the person's identity. In the third aspect we dealt with the reinforcement family caregivers gained through their social role as caregivers, and in the last aspect we found that some interviewees were grasping the caregiving role as a means of coping with loneliness or emptiness.

Hochschild (1979, 2012) recognized the productive work of detachment as an active emotional choice, by putting aside a certain feeling in the interest of completing one's job. Professional staff members often describe detachment as a failure to engage or as burnout (Bamford et al., 2018). However, under certain circumstances, detachment can increase engagement (Bailey et al., 2015).

We found that for all the interviewees, some sort of emotional and physical detachment was supportive of their ability to provide care. The emotion work of sliding between involvement and detachment was performed through framing care as a task or project, by pre limiting visiting time, objectification of the person they cared for, minimizing touch, or trying to separate other aspects of their life from the role of caregiver. All these strategies enabled emotional detachment, which in turn enabled reduction of negative emotions, such as anger, revulsion, sadness, and grief. Once this reduction was achieved it enabled engagement, so caring could be enacted with better empathy and attendance to their relative's needs. Furthermore, being able to be empathic and attending (i.e., feeling engagement), further strengthened the notion that detachment is legitimate and fruitful. In summary, some detachment is required to keep some engagement intact and vice versa. Nevertheless, an energy consuming tension remained between the requirement of feeling empathic, the feeling rule and the need for detachment.

Another emotion work enabling strategy we described here, was creating an inner separation mechanism that allowed participants to separate the person from their condition. Most of the interviewees approached the person in a personalized manner, for example, referring to the relationship they had, or to the person they had known and loved in the past. However, when they referred to their current condition and its complexities, they used a non-personalized approach, referring to the symptoms and the disease. This approach enabled the family caregivers to maintain positive emotions and attitudes towards their family member, while at the same time holding and expressing negative emotions, such as anger and frustration. This resonated with previous arguments in the literature regarding family caregivers of people with dementia. Nichols et al. (2013) highlighted that attributing the behavioral disturbance to the dementia rather than the individual contributed as a coping strategy. However, like Herron et al. (2019), we illustrated that this may also reflect the family caregivers' attempt to preserve a positive sense of self. This attitude may produce a beneficial environment in which the burden will be reduced, and the family caregivers' experience will become more positive with meaningful.

The third sub theme that emerged in our study suggests that adopting/maintaining the role of caregiver gave many of our participants a sense of a meaningful position in their community. Their role was framed not only as a relationship between the caregiver and the cared for, but also as a social and community based one. Social traditions and moral expectations shaped the perception of caring. The role of a family member caregiver was described in many of the interviews as part of the identity as a family member and a community member.

Studies suggested that family caregivers of people with dementia are at risk for social isolation (Kovaleva et al., 2018; Victor et al., 2020). The last theme we described was related to feelings of loneliness and emptiness, that can stem from three different reasons. First is the loneliness and emptiness caused by being occupied with care itself; the second reason is the caregiver's life circumstances (e.g., the absence of accessible support of the immediate social circle or other meaningful action); and the third reason is the fear of feeling alone once the family member dies, despite the very limited interaction with him/her. Fear of loneliness was found as significantly influencing family caregivers' reluctance to give up their caregiving role (Hagen, 2001), in spite of the fact that when compared, caregiving spouses of people with dementia reported significantly higher levels of loneliness than did non caregiving spouses (Beeson, 2003).

The context of this study is Israeli society. Israel is defined as democratic state and is Westernized to a great extent. Nevertheless, tradition plays an important role in both Jewish and Arab populations (Zamir et al., 2020). For example, over 50% of Israeli Jews define themselves as traditional or religious, and over 80% believe in God (Arian & Keissar Sugarmen, 2009). Israeli society is characterized by being on the continuum between individualistic to collectivistic cultures (Abbou

et al., 2017). Despite Western society ageism, Israeli tradition considers the elderly to be central pillars of society and holds them in great respect (Zamir et al., 2020). In both the Arab and Jewish traditions, caring for an individual is not just a matter of physical support. In the Jewish community, social support includes visiting the patient and caring for him/her (Dorff, 2005). The Muslim religion of the Arab group also encourages caring for the needy, stating that spiritual growth will be awarded in the face of hardship against the difficulties of care (Farhadi et al., 2019).

Since Israeli society is culturally diverse, it allows for exploration of the impact of culture on the meaning of caregiving in different communities. Indeed, our study illustrates how cultural background influenced the motivation for and the perception of caring among the participants. These cultural characteristics tailored the nature and content of the emotion work and feeling rules used by the family caregivers.

Worldwide, most people with dementia live in the community and are cared by family caregivers (e.g., spouse and/or adult children). In Israel, 89% of the people with dementia live at home (Azaiza & Brodsky, 2003; Van der Steen et al., 2017), and when looking at traditional communities, both Jewish and Muslim, the numbers are even higher (AboJabel et al., 2021). Filial commitment and norms rely on an instrumental structure, such as practical needs (Qadir et al., 2013), and are considered valuable in Israel in general and among the traditional populations in particular, more than in European countries (Lowenstein et al., 2007). People from traditional communities emphasized the role played by religion or highlighted familial responsibilities (Farhadi et al., 2019; Quinn et al., 2010).

We argue that being part of traditional society, as reflected in our interviews, was associated with having more feeling rules on the one hand, but also with having more support with coping and bridging over the gap between the feeling rules and the "true" feelings on the other. However, these emotion work and feeling rules can further increase one's emotional burden when family caregivers struggle to fulfill these high expectations, thus, contributing to their poor wellbeing (Simpson & Acton, 2013).

In the case of family caregivers, the guidance for feeling rules is determined, among other factors, by the cultural and familial background as a social role. Emotion work enabled the family caregivers to diminish the sense of burden and support their loved one in the long journey of care.

Strength and limitations

Our study has several strengths. We focused on the specific group of people with end stage dementia, which has not been extensively studied regarding caregiving burden and emotion work. By recruiting family caregivers from units specializing in end of life care, we were able to describe themes that concerned care specifically for people with end stage dementia. The use of in depth interviews strengthens our results (Queirós & Faria, 2017). Our study adds a unique perspective by adopting the term "emotion work" to family caregivers' coping strategies.

However, our study has several limitations. Although an attempt had been made to sample a multi-cultural population from different parts of the country, some cultures are underrepresented or missing. Although the sample size was relatively large for a qualitative study, it cannot be assumed that the findings are typical of all family caregivers' populations, thus, the findings may not necessarily be applicable or generalizable to other cultures, other Health Maintenance Organizations, or other countries. In addition, most previous literature on family caregivers for people with dementia had not focused on exploring the various aspects and meanings of the emotion work they perform. In order to develop the insights of this current work there is a need for further longitudinal studies, in various cultural contexts.

Conclusions and implications

At the end stage of the dementia, family caregivers are faced with high levels of physical and emotional burdens. In this study we have discussed the emotional coping strategies family caregivers perform in order to maintain day to day engagement and care, despite the high level burden.

We found that emotion work and feeling rules, terms adopted from the theory on professional service providers, can provide a useful conceptual framework to unpack and understand coping strategies of family members struggling with the burden of caring for people with end stage dementia. We also showed that the individual's emotion work is tailored by the cultural and social background.

Understanding the role of emotion work in coping, acknowledging what family caregivers present as feeling rules, and awareness of the gaps between what is presented and what can be the "true feelings" can help professional staff members who treat people with end stage dementia to better support family caregivers. Recognition of the cultural and religious influence on the emotion work components can induce a better people centered approach.

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Ethical approval

The study was approved by the local Ethics Committee and adhered to the tenets of the Helsinki-Declaration of 1975 (BBL00118-17).

ORCID iD

Inbal Halevi Hochwald  <https://orcid.org/0000-0002-4930-2072>

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Inbal Halevi Hochwald (RN MPH) is a lecturer at the Academic College of Emek Yezreel, and a PHD candidate at Ariel University, Israel. Inbal worked as a primary care practitioner with considerable experience with palliative and geriatric care. Her work is focused on aspects of old age health, homecare, palliative care, public health, and health ethics in multi-cultural society

Daniella Arieli (PhD) is a senior lecturer at the Academic College of Emek Yezreel, Israel. Daniella is a social anthropologist and an action researcher who works in the field of inter-group and inter-cultural encounters. Much of her work is focused on various aspects of old age health, such as communication and dementia, homecare relationships, migrant care workers, doctor–patient communication, education to caring in diverse and complex societies.

Zorian Radomyslasky (MD, MHA) is a specialist in Family Medicine and in Geriatric Medicine, has been the Sirdar medical clinic of the Israel Defense Forces, the Director geriatric service of MHO Maccabi. Manager and lector of gerontology direction in Ariel University.

Yehuda Danon (MD) is specialized in pediatrics and immunology who has been the Surgeon General of the Israel Defense Forces, the Director General of Beilenson Medical Center, the founder and director of the Schneider Children's Medical Center of Tel-Aviv University and a President of Ariel University.

Rachel Nissanholtz-Gannot (LLB, LLM, PhD. Adv.) is a Professor at the Health System Management department at Ariel University. She also serves as a research scholar at the Smokler Centre of Myers-JDC-Brookdale Institute in Jerusalem. Rachel is a lawyer, and her research focus is on health policy issues as well as medical ethics, end of life issues and patient centered care.