題目(和文)	家族介護者の役割喪失感と医療専門家との交流による家族介護者の役割の形成に関する研究
Title(English)	A study on a family caregiver ’ s sense of role loss and the shaping of the family caregiver role through interactions with healthcare professionals
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Type(English)	Doctoral Thesis

A study on a family caregiver’s sense of role loss and the shaping of the family caregiver role through interactions with healthcare professionals

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A Thesis Submitted in Partial Fulfillment of the Requirements for the Doctoral Degree

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March 2022

Abstract

Family caregivers are unpaid health workers and may be considered hidden patients of the care recipient's physician. They are members of the healthcare team caring closest to the care recipient and members of the unit of care; their concerns, needs, and health must be paid attention to and addressed. This study aimed to understand the family caregiver's caregiving experience from a role performance angle. Firstly, this was achieved through understanding the impact of a family caregiver's sense of role loss on the caregiving experience where the unit of analysis was the caregiver. Next, this study examined the shaping of caregiver role through interactions with health professionals, based on tasks and actions, with the caregiver and the healthcare professional as the unit of analysis. The findings shed light on a sense of caregiver role loss, the possibility of generating it through role rotation, and its use as a tool to maintain a sense of personal choice in life and self-priority. This study contributed to advancing knowledge of the caregiving experience, in different caregiving settings, based on an individual's primary role and role transitions. Furthermore, two different role shaping processes were found: fixed with tasks and expected actions, and dynamic tasks and actions often transformed. The contrast between healthcare professionals and the caregiver's perspectives of tasks and actions showed that the source of their practice-based knowledge differs; family caregivers possess the latest knowledge about the care recipient due to the close relationship and delivery of care. A strong support system can help family caregivers practice role rotation more often. Informational and emotional support increase their preparedness to deal with the circumstances at hand. Family caregivers are highly contextual practice-based knowledge holders who, when used effectively, may help craft tailor-maid treatments centered on the care recipient.

Acknowledgments

This has been a rocky road. The accomplishments of the past three years are not a one-person's feat. My deep gratitude to Prof. Senoo for the guidance and encouragement: without your support this would not have realized.

Thank you to Prof. Ho for the help and contribution to this work.

Prof. Seaborn, Prof. Nishida, Prof. Xiuzhu, and Prof. Kezuka, members of the evaluation board: thank you for kindly reviewing the thesis and concretely pointing out the parts that needed attention. There is clear improvement to this document after attending to your suggestions.

Ishida-san, Sekino-san and laboratory mates: support much appreciated.

Thank you to Otsuka Toshimi Scholarship Foundation, Mitsubishi Corporation International Scholarship and Tokyo Tech for the financial support. Appreciate Student Support Division support during this course and WISE-SSS for the chance to broaden my view.

Thank you very much to the family caregivers' associations and the respondents of the surveys in this study.

Thank you, Japan and the Japanese, for believing in me and giving me the opportunity 13 years ago.

Thank you to all my friends and family for being there every step of the way.

Revision list based on suggestions and comments received from the Evaluation Board Members in pre-screening presentation (2021-12-23)

Prof. SEABORN Katie | シーボーン ケイティー	
Comment	**Revision**
1. What does "produce health" mean?	Expression revised.
2. You cite Hasselkus (1988) and others (Table 1) with respect to "role loss." What does your work add?	Table 11 added with the contribution of the study.
3. Did you use multiple raters? If not, why not? If so, where are the inter-rater reliability analyses?	They were not used. Data analysis was accompanied by thorough text analysis to ensure the interpretations were accurate. This analysis and the R source code was added to Chapter 3 (section "3.1.2. Text analysis").
4. Are there any concerns about relying on Google Translate? It is notoriously incorrect when it comes to translating nuance, metaphorical language, and even gender of the subjects.	Addressed in p. 61. Google translate was used to streamline the translation process. However, each answer was checked to ensure nuances, metaphorical language and gender were correctly captured. This check happened multiple times.
5. You outline high-level practical strategies and tools. Do you have a sense of how to carry these out in detail?	Addressed in Chapter 5, pp. 85-86.
6. Are you familiar with the ideas of intrinsic and extrinsic well-being? Ryan, Deci, etc.	A little familiar with their concepts of Intrinsic and Extrinsic Motivations, Self-Determination Theory. Not explored in this study in the context of caregiving and family caregiver role.
7. Why "assumption" and not "hypothesis"?	The word "assumption" was used as they were drawn from existing theories and past studies' findings that composed the theoretical framework of the thesis.
8. You used a lot of theories, and they were different between studies 1 and 2. What is the theoretical connection between the studies? It would be useful to have a table or figure linking the contributions of your work to each of the theories.	Addressed in Chapter 5, Table 15, p. 85.
9. How do you position your work within the department/discipline?	Believe the study is aligned with service provision in healthcare, knowledge creation and sharing through interactions when one performs in a role.

10. The second study had far less participants. Can you comment on this?	This was a limitation of this study. The turn out of respondents was lower than expected. For the subsequent study, we changed our strategy to recruit respondents and had better results.
11. Can ba be trained or does it just naturally emerge?	According to Nonaka and Konno (1998), ba can occur in informal circles, project teams, e-mail groups, online forums, vacation, so in this study we assumed it can be trained as well.
12. Revise the second para on p. 10.	Revised.
13. Figures esp. Fig. 1: Use capitalization consistently.	Standardized.
14. Revise first sentence in first para on p. 11.	Revised.
15. Last para on p. 11 and first para on p. 12 seem to speak to the same thing, so combine.	The two paragraphs were revised to avoid redundancy but kept separate.
16. Rather than refer to the numbers of questions, please briefly describe them (the reader can’t remember).	Foot notes with the questions were added for convenience.
17. Propose a starting point of a framework that will help us better understand caregiving.	Addressed in pp. 85-86. The conceptualization of the family caregiver as a member of the care team is explored and its expected impact on intersubjectivity and the practice of deference to expertise were contextualized within caregiving. The framework must draw the caregiving experience as a myriad of interconnected components.

Prof. XIUZHU Gu | 顧 秀珠

Comment	Revision
1. Include findings and conclusions in the Abstract.	The Abstract was revised.
2. In Study 1, In the questionnaire, which part did you ask for the role loss in the survey? Clarify that in the thesis.	Addressed in p. 28.
3. In Study 1, use the ERA framework. Could simplify the analysis.	An analysis with two phases aimed first at granularity. ERA was used to consolidate and arrive at the top raking themes.
4. In Study 1, is it necessary to use score? No need for scores.	Scores were used to filter themes and build a ranking to facilitate the data interpretation.
5. In Study 1, Actions/mitigation is better to be matched with Experience and Reflection to clarify with to see the implications.	Chapter 3, sections “3.2.3. Action” and “3.3. Discussion” were revised to ensure the text conveyed this with more clarity.

6. In Study 2, revise sample size in thesis.	Revised.
7. In Study 2, medicine is not technology.	Figures revised.
8. In Study 2, translation using google translate not advised.	Addressed in p. 61. Google translate was used to streamline the translation process. However, each answer was checked to ensure nuances, metaphorical language and gender were correctly captured. This check happened multiple times.
9. In Study 2, explain and include the interactions.	Section "4.3.3. Analysis 3: contrasting co-occurrence networks of words" fully revised, excerpts from answers included.
10. RQ1 Impact Sense of role loss ⇒ Experience (Experience → Reflection → Action) ↓ ↓ feeling (as cited in the definition) feeling also included (e.g., Table 8, statements about feeling of role loss) It makes readers confused that in RQ1, you make "sense of role loss" and "experience" as different issues; but in your analysis, it seems that "experience" includes "sense of role loss".	Addressed in pp. 50-51. Indeed, this was not clear. Entire text was revised. It was explained that the caregiving experience is composed by many elements, being sense of role loss, role rotation, sense of personal choice in life and self-priority some of them. The study allowed us to see how these components, influence one another and, ultimately, impact the experience back.

<table>
<tr><th colspan="2">Prof. NISHIDA Yoshifumi | 西田 佳史</th></tr>
<tr><th>Comment</th><th>Revision</th></tr>
<tr><td>1. Reflection is very important, even with same experience, reflection is shaped differently.</td><td>Indeed, the data confirmed Montgomery and Kosloski (2009, 2013) claims that caregiving is always unique.</td></tr>
<tr><td>2. To understand the process of role shaping. Show the examples of dynamic role shaping process from the answers. What is the dynamic process of role shaping?</td><td>Section "4.3.3. Analysis 3: contrasting co-occurrence networks of words" fully revised, excerpts from answers included.</td></tr>
</table>

<table>
<tr><th colspan="2">Prof. KEZUKA Kazuhiro | 毛塚 和宏</th></tr>
<tr><th>Comment</th><th>Revision</th></tr>
</table>

1. In Chapter 2, improve structure and meaning from these theories.	Chapter 2 was revised to fill identified gaps.
2. Why sense of role loss is so important in the academic sense? explain why the concept is important.	Addressed in p. 21.
3. Sample from different countries, any difference in culture or healthcare system. Add this to limitation.	Addressed in p. 62.
4. Perform language check.	The entire thesis text was revised by the researcher. After that, a professional language check service was used to improve readability of the text.
5. Correct tables and figure numbers.	Corrected.
6. In Study 2, show some raw data, not only the abstract output.	Section "4.3.3. Analysis 3: contrasting co-occurrence networks of words" fully revised, excerpts from answers included.

<table>
<tr><th colspan="2">Prof. SENOO Dai | 妹尾 大</th></tr>
<tr><th>Comment</th><th>Revision</th></tr>
<tr><td>1. Change long sentences to word</td><td>The entire thesis text was revised by the researcher. After that, a professional language check service was used to improve readability of the text.</td></tr>
<tr><td>2. Improve structure and meaning from these theories, explain linkage.</td><td>Chapter 2 was revised to fill identified gaps.</td></tr>
<tr><td>3. In Chapter 4, revise output, show some raw data.</td><td>Section "4.3.3. Analysis 3: contrasting co-occurrence networks of words" fully revised, excerpts from answers included.</td></tr>
</table>

Table of Contents

List of Figures

List of tables

Dedicated to those who cared, are caring, or will care for a loved one.

And to my parents.

Chapter 1 - Introduction

Governments are gradually developing strong community-based approaches to facilitate home care. Home care aims to satisfy social and healthcare needs through formal and informal caregivers providing high-quality and affordable services in people's homes (Tarricone and Tsouros, 2008, p. 1). This is a response to people's preference to be under home care instead of living and receiving care at an institution (Tarricone and Tsouros, 2008, p. 2). Furthermore, services provided in the patient's home environment are more cost effective than institutions, particularly if informal care is available and used effectively (Genet et al., 2012, p. 2).

Home care is part of a patient-centered approach focused on the recipient's needs, their autonomy, and respect for them, the objectives of which must be negotiated with the family members (Sanerma et al., 2020). This may be viewed as the effect of a model where the patient is seen as a "whole by focusing on the treatment of illness, and not just on the removal of the symptoms of a disease" (Hojat, 2016, p. 120).

With the patient occupying the center of the caring process, health professionals have started seeing patients as active participants in the treatments, thus co-creating value, and increasing the technical and functional quality of healthcare services and patient well-being (Zhao et al., 2015). Existing studies have focused on the patient-physician (care recipient and healthcare professionals, respectively) relationship.

In the home care arrangement, caregiving also moves to the center of the home environment. The family caregiver unites with the care recipient in a dyad (Coeling et al., 2003) and moves to the center of the caring process. Caregivers play a critical part in the operations and delivery of care at the last mile (i.e., the home environment). Family caregivers are active participants in the treatment, heavily contributing to its effectiveness.

1.1. Caregiving and family caregivers

Caregiving is an activity directed at a person with a disabling condition or illness rendering them unable to care for themselves; caregiving has three main objectives: to get things done, to realize a sense of health and well-being for the care recipient, and to establish a sense of health and well-being for the caregiver (Hasselkus, 1989). The outcomes associated with the activity vary from positive to negative, such as life satisfaction, personal growth through learning opportunities (Marino et al., 2017), caregiving stress, role captivity (Quinn et al., 2019), objective and subjective caregiver burden (Metzelthin et al., 2017), less time for other activities, financial pressure, and tiredness (Turcotte, 2013).

Family caregivers are unpaid health workers and may be considered hidden patients of the care recipient’s physician (Haug, 1994). They are members of the healthcare team closest to the care recipient and members of the unit of care whose concerns, needs, and health must be paid attention to and addressed (Sherman, 2019). These family caregivers are essential to healthcare systems. For instance, the American Association of Retired Persons (AARP) estimates that in 2017, family caregivers delivered 34 million hours of care in the US alone with an estimated unpaid contribution of 470 billion dollars (Reinhard et al., 2019). These numbers are expected to rise as populations age (Winter et al., 2010).

An investigation of family caregivers’ experience and perceptions of their role showed they carry out various tasks. (i) Family caregivers are an unpaid resource to the health system as many of their tasks are part of the caregiving definition; (ii) they see themselves as co-workers, part of the care team, who feel empowered when they share knowledge and information about the care recipient; (iii) most do not see themselves as co-clients, and they expect help from the care team, though professional acknowledgment and support were key to their well-being; (iv) lastly, several describe themselves as “care coordinators” where they gather and organize information, and are researchers or problem solvers deciding on the best course of action (Law et al., 2021). Family caregivers are responsible for both the operations of the caregiving activity and its management and communication to others; the family caregiver role seldom lacks challenges.

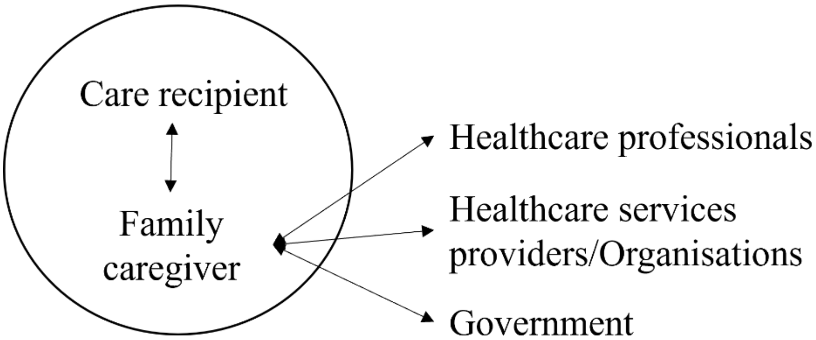

Figure 1. Caregiving fields: internal and external

Family caregivers perform tasks in two complementary fields, illustrated in Figure 1. The caregiver mainly operates one internal aspect to accomplish the caregiving objectives; constituted of the family caregiver and the care recipient dyad who interact with each other, primarily in the home environment. The other external field involves family caregivers coordinating the care with multiple parties (i.e., health professionals, service providers, government, etc.) through interactions. Family caregivers seek to have their concerns heard, acknowledged, and supported by health professionals; it may occur in the home and public environments (i.e., physician's office, hospital, government offices).

A basic caregiving stakeholder's map, displayed in Figure 2, is composed of:

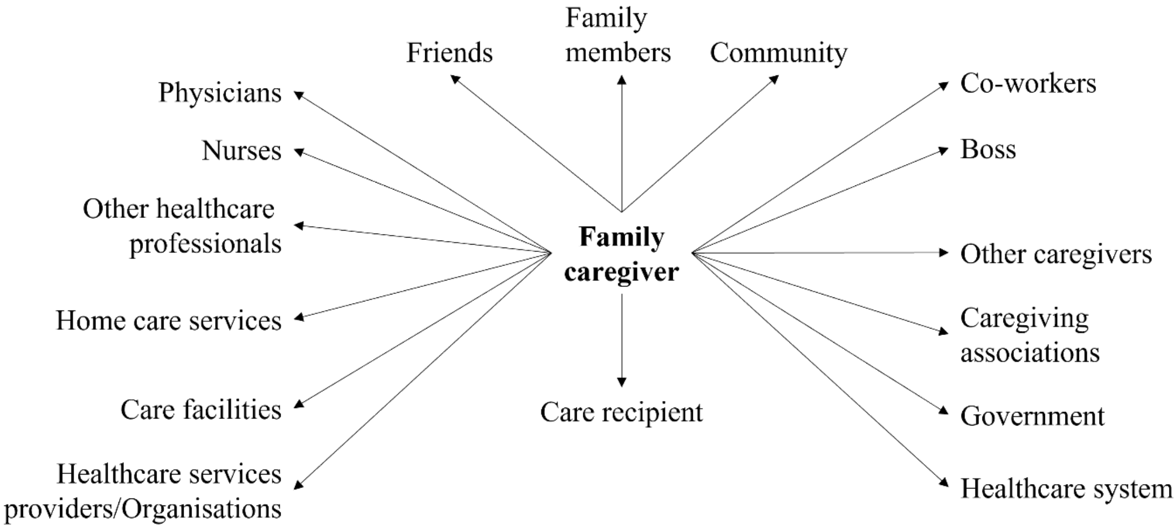

Figure 2. Caregiving stakeholder's map.

Caregiving is complex as the stakeholders' map portrays. Effective support for family care must encompass tailored solutions that will account for the uniqueness of each caregiving experience (Montgomery and Kosloski, 2009) within these two fields. Well-supported family caregivers can deliver care at the last mile benefiting the parties involved.

Motivated by the contribution family caregivers provide to the care recipient, other family members, and the healthcare system, the researcher set out to understand the role of the caregiver, the scope of tasks and actions, how it is shaped, and the tolls on the lives of those performing the service. Discover ways in which family caregivers' caregiving experience can be improved while performing in the caregiver role and being effectively used by patient-centred and home care approaches to ensure treatment success.

This thesis aimed to understand the family caregiver's experience from a role performance angle and provide suggestions to help improve their caregiving experiences. This goal was achieved through understanding the impact of a family caregiver's sense of role loss on the caregiving experience, with the unit of analysis as the caregiver (Study 1 in Chapter 3). The study also examined the shaping of the family caregiver role through interactions with healthcare professionals, based on tasks and actions with the caregiver and the healthcare professional as the unit of analysis (Study 2 in Chapter 4). Each study covered one part of the internal and external fields.

1.2. A family caregiver’s sense of role loss

While caring for another person, family caregivers go through personal changes and transitions. They reportedly have a powerful sense of role loss when sensing a change in role or responsibility, relationship distancing, or a changed asymmetry (Hasselkus, 1988) throughout the caring process. Little is known about how this sense of role loss impacts caregiving experience. It is necessary to clarify the phenomenon of sense of role loss, its causes, and triggers, how it impacts the caregiver’s experience back, how this impact differs among caregiving settings, and uncover mechanisms deployed to deal with it in each setting.

Many family caregivers focus exclusively on the caregiving activity. The caregiver role becomes their primary role, the role most central to an individual’s identity (Amah, 2009) or the role one performs more frequently. In a subjective ranking system, individuals have primary, secondary, tertiary roles, and so on, contributing to shaping their identity to differing degrees. Other caregivers have different primary roles while carrying out tasks. For instance, it is not uncommon for them to hold the primary role of a worker while juggling caregiving tasks.

Research shows that those caring for patients with mental disabilities experienced fewer stress outcomes as they spent more hours involved with outside work (Bainbridge et al., 2006). Other findings suggest that family caregivers may benefit from being employed when caring for cancer survivors (Kim et al., 2006). This study assumed stress outcome and benefiting from being employed would influence the caregiving experiences. Thus, it was further assumed that holding the primary caregiver role would generate a sense of role loss that would yield different caregiving experiences. It was necessary to consider these nuances produced by different configurations of care based on this role raking to support family caregivers more effectively.

Past studies shed light on the family caregivers’ experience regarding identity, condition, illness, or gender. However, it remains unclear whether the primary role was the caregiver role and how this variability in the caregiving setting corresponds with the reported sense of role loss. These studies did not consider the caregiver's primary role, and most of them simply reported the phenomenon with brief mentions of mitigation strategies. In an attempt to fill this gap, this research formulated the following research question (RQ1) for Study 1:

How does a family caregiver’s sense of role loss impact the caregiving experience?

The objective of Study 1 was to understand the impact of a sense of role loss by contrasting family caregivers' experiences in different groups, where each group configures a different caregiving setting. The settings are as follows: when an individual's primary role changed to the caregiver role after caregiving commenced; when their primary role was other than the caregiver role after commencement; when their primary role was the caregiver role before caregiving started.

One of this study's contributions is illuminating a new perspective of role loss: the sense of caregiver role loss that can occur when one rotates through held role and work as a tool, with implications on the caregiver's sense of personal choice in life and self-priority. Furthermore, this phenomenon was researched based on the primary role and role transition (with focus on role exit), then the groups' experiences were contrasted. Prior studies account for caregivers' experiences based on identity, condition, illness, and gender; this study can contribute with additional settings.

Study 1 is potentially the first to analyze this phenomenon in different caregiving settings, based on an individual's primary role and role transitions. It offers a new perspective by understanding how the phenomenon arises, its nuances, and impact on the caregiver's experience.

1.3. Shaping the family caregiver role through interactions with the healthcare professional

Family caregivers are essential to healthcare systems, delivering care at the last mile, coordinating what is necessary with other parties, and forming a dyad with the care recipient. Interactions with healthcare providers help build informational and emotional support that will be used by the family caregiver while performing in the caregiver role. It can greatly contribute to an effective performance and a higher sense of control over and preparedness to deal with situations at hand. However, family caregivers may sometimes feel left out of medical decisions, be confronted with unrealistic expectations, or receive comments about their abilities that affect them negatively (Law et al., 2021).

Research recognizes that decision-making processes during treatment are informed by relationships (Epstein and Street, 2011), and such decisions impact both the patient and the family caregiver (Laidsaar-Powell et al., 2017). However, patient-centered care provisions may not place the family caregiver in its center. They can be regarded as hidden patients who feel empowered through sharing their knowledge about the care recipient. They are, however, frequently neglected by health care systems (Sherman, 2019).

For many, being a family caregiver and settling into this role is a process that spans years. Health professionals may support the shaping of the role through gradual teaching, guidance, and assignment of tasks and actions. However, little is known about how interactions with healthcare professionals influence the shaping of the caregiver role from a tasks and actions perspective. To gain understanding, Study 2 was guided by the following research question (RQ2):

How is the family caregiver role shaped through interactions between the family caregiver and the healthcare professional?

Study 2 aimed to contrast the healthcare professional and the family caregiver's perspective, from a tasks and actions perspective, to understand how the caregiver role is shaped during the treatment. The findings suggested that interactions with healthcare professionals resulted in a pre-defined shape for the family caregiver role; there were fixed tasks and actions, and the family caregiver was expected to behave according to expectations. There was little room for reflection or negotiation. Shared information or knowledge was limited to these fixed tasks and expected actions.

Interactions with the care recipient meant that the daily demands of the caregiving activity and the dyadic structure of the care recipient-family caregiver relationship imposed constant negotiation and transformation of tasks and actions, so the role continued to be relevant. With this, the family caregiver could continue to provide the most suitable and customized care to the recipient, based on the circumstance at hand. The list of tasks and actions was often revised and renewed, and the shaping of the role was a continuous process.

In summary, when interacting with healthcare professionals, the family caregiver role was shaped *by* the care recipient and their condition. When interacting with the care recipient, the role was shaped *with* them. As a result, it was concluded that family caregivers are holders of highly contextual practice-based knowledge that can greatly contribute to building a targeted and effective treatment tailored to the care recipient.

Study 2 indicated that, through the different processes of role shaping, the source of contextual practice-based knowledge that healthcare professionals possess differs from the family caregivers. Additionally, family caregivers possess the latest knowledge about the care recipient due to the close relationship and delivery of care; they can greatly contribute to designing a targeted treatment tailor-made for the care recipient.

In summation, family caregivers aid in establishing patient-centered approaches. This is probably the first study that contrasted tasks and actions (expected to be) carried out by the healthcare professionals and caregivers and how their interactions influenced the shaping of the family caregiver role.

1.4. Outline of the thesis

This thesis is composed of five chapters, illustrated in Figure 3:

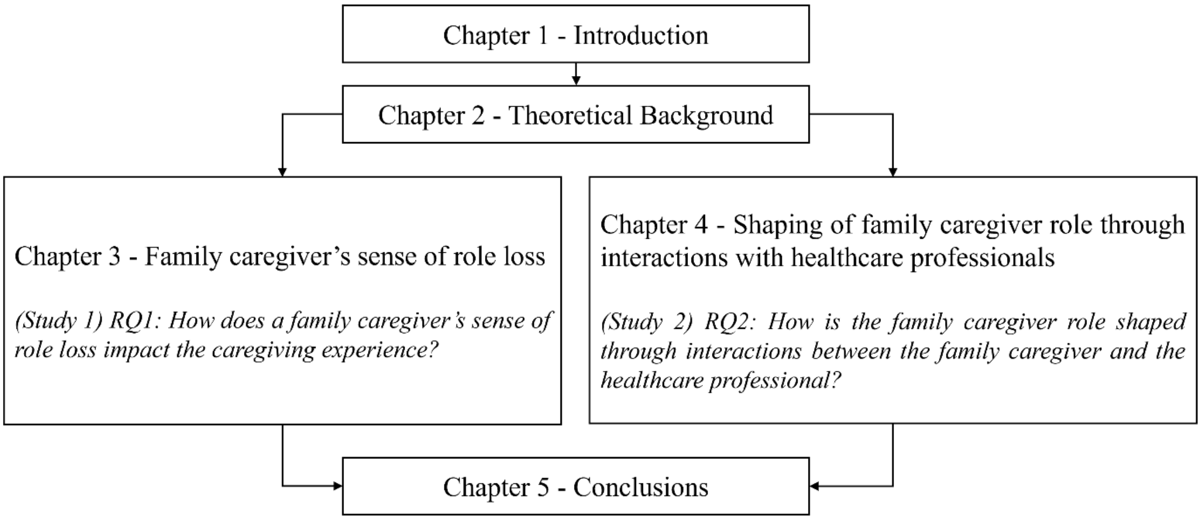

Figure 3. Thesis outline

"Chapter 2 - Theoretical background" extends this chapter through a literature review of concepts and theories relevant to this thesis. This work's theoretical framework comprises Role Exit Theory, Role Transitions Theory, Caregiver Identity Theory, Actor-Network Theory, Cultural-Historical Activity Theory, and Nonaka and Konno's Ba, within the context of the family caregiving. The research problems guide this literature review and questions presented in this chapter, and it will serve as the theoretical foundation for answering the research questions based on data analysis and discussion in the subsequent chapters.

"Chapter 3 - A family caregiver's sense of role loss" addresses RQ1 through Study 1 and explores the impact of a family caregiver's sense of role loss on the caregiving experience. This study draws heavily from sense of role loss, role, role exit, and role transitions theories, which provide the theoretical foundation to analyze family caregivers' transitions while caring for another person. An online survey was conducted to capture the experience of this transition, and 66 responses were grouped based on the respondents' primary role. Three distinct groups emerged; their answers went through thematic analysis and were contrasted to understand the differences in the impact that sense of role loss had in their caregiving experience. The conclusion, implications, and limitations are presented, focusing on the family caregiver.

“Chapter 4 - Shaping the family caregiver role through interactions with healthcare professionals” addresses RQ2 through Study 2 and explores how the interaction of healthcare professionals and family caregivers contribute to the shaping of the caregiver role. Actor-Network Theory, Cultural-Historical Activity Theory, and Nonaka and Konno’s ba serve as the theoretical framework for the analysis. The 21 answers to an online survey were interpreted and analyzed through a framework and text analysis. The results are discussed, and implications are presented, with the focus expanded to include the healthcare professional.

“Chapter 5 - Conclusions” returns to the research questions and objectives, presenting the study’s final remarks. The authors recognize that each caregiving experience is unique, and family caregivers possess highly contextual practice-based knowledge. Along with the care recipients, they are the gatekeepers to the context of the illness. Providing opportunities to share this knowledge, seeking improvement, and effectively supporting family caregivers can increase the chances of designing effective and tailor-made treatments.

Chapter 2 - Theoretical Background

2.1. A family caregiver's sense of role loss

A sense of role loss resembles what Ebaugh identified as "the vacuum" experienced by those who go through a voluntary role exit process (Ebaugh, 1988, p. 143) and find themselves in a roleless state, which places an individual in a liminal phase when their role identity is ambiguous (Ashforth, 2000, pp. 135-136). For family caregivers and concerning the performance in this role, the ambiguity between the tasks they are currently carrying out and how they see themselves (i.e., their role identity in relation to the other and the tasks they carry out based on it) causes distress (Montgomery and Kosloski, 2013, p. 137), affecting them negatively and impacting their caregiving experience.

A role may be defined as a set of expected positional behaviors in a social group that includes a social position with normative expectations to be enacted through the individual's behavior (Allen and Van de Vliert, 1984). These behavior patterns are learned, and role performance encompasses tasks and skills (Schindler, 2008). This study treats a primary role as the role most central to an individual's identity (Amah, 2009) or the role one performs more frequently. In a subjective ranking system, individuals' roles include primary, secondary, tertiary, and so on, shaping their identity in differing degrees.

The family caregiver role emerges from an existing relationship and should be seen as its transformation, holding strong meaning to those performing in it and regulated by norms or social rules (Montgomery and Kosloski, 2009). This transformation results in ambiguity between tasks and role identity, leading to the reported sense of role loss. For instance, a husband-caregiver role can be seen as transforming a husband's role.

According to Zena Blau, a role exit occurs "whenever any stable pattern of interaction and shared activities between two or more persons ceases" (Ebaugh, 1988, pp. 13, 14), defined as a "process of disengagement from a role that is central to one's self-identity and the reestablishment of an identity in a new role that takes into account one's ex-role" (Ebaugh, 1988, p. 1). It is suggested that the extent to which the exit is problematic depends on how the exit occurred and the options available for new, valued roles after exiting (Blau, 1973; in Mancini, 1975, p. 1). Family caregivers may fully exit a prior role and create the "ex-role" or not, but a sense of role loss is a reported experience.

It is not felt exclusively by family caregivers and, as people transition through roles, role loss and gain constantly occur (Scott et al., 2014). Within the same role, the required performance changes over time as one goes through planned and unplanned life transitions

(Scott et al., 2017), resulting in macro or micro role transitions. Table 1 consolidates studies that highlighted the experience of a sense of role loss when life transitions occurred.

Table 1. Studies about the sense of role loss

Study	When It Is Felt	By Whom	Cause/s	Mitigation
Hasselkus (1988)	Throughout caregiving	Family caregiver	Change in role and responsibility; Relationship distancing or a changed asymmetry	
Dellasega et al. (1995)	After the care recipient's placement in a nursing home	Family caregiver	Nursing home placement	Redefinition of the caregiver role (expressed longing to resume prior roles)
Kellett (1998)	After the care recipient's placement in a nursing home	Family caregiver	Sensed change in engaged involvement	Finding new ways of caring for the relative
Kim and Moen (2002)	Upon and after retirement	Retiree	Exiting role central to identity and environmental loss accompanying the role exit	
Williams (2014, p. 106)	Foster child arrival at or departure from the family	Birth Children	Place or position constant re-alignment to accommodate a foster child	
Tummala-Narra and Deshpande (2018, p. 175)	Post-immigration	Immigrant	When shifts in power, respect, and authority within the families occur	

Macro role transitions occur when an individual moves between sequentially held roles. They are less frequent and may involve more or less permanent changes (Ashforth, 2000, p. 7). One disengages from a role (role exit) and engages in another (role entry) (e.g., placement of the care recipient in a nursing home and ceasing the caregiver's full care activity), a process that can be lengthy and demanding. Regularly, individuals go through micro role transitions. They psychologically (and, sometimes, physically) move through simultaneously held roles in short periods, comprising temporary and recurrent role exits and entries (Ashforth, 2000, p. 261). One holds multiple roles and, depending on the context in which the individual finds themselves, a specific role is occupied while others remain in the background.

Much is yet to be uncovered regarding the family caregiver's sense of role loss, its connection to roles exits and transitions, its impacts on the caregiving experience, and how individuals deal with such a sense. In the caregiving context, role changes within the family can occur quickly, extend for a short or long time, or be permanent, resulting in difficulty for caregivers to adjust to the impact of the care recipient’s illness. Some individuals experience role loss or gain, or view the change as an extension of an existing role (Braine and Wray, 2018, p. 122).

Although each caregiving situation is unique (Montgomery and Kosloski, 2009), similarities in caregiver roles indicate that (i) the majority are female family members; (ii) the activity changes over time; (iii) caregiving leads to changes in relationships and identities of both the caregiver and the care recipient; (iv) caregiving is accompanied by stress and burden impacting the caregiver’s well-being; (v) there are positive outcomes, such as self-satisfaction and sense of mastery (Montgomery and Talley, 2013, pp. 177-182).

Despite these similarities, the caregiving experience varies widely across groups and within the same group of caregivers (Montgomery and Kosloski, 2009; Lowes et al., 2016; Maguire and Maguire, 2020). It is associated with caregiving esteem and schedule burden (Sautter et al., 2014) and the degree of involvement in personal care, increasing emotional and psychological burden (Halpern et al., 2017). Although caregiving is perceived as rewarding and a positive experience is associated with improved mental health, the responsibilities reduce the caregiver’s time for recreation or personal activities (Sandstedt et al., 2018).

Family caregivers are a unique type of practitioner because the role emerges from existing relationships (Montgomery and Kosloski, 2009). It is a demanding role because they are members of the healthcare team providing care daily, and, at times, they may become second-order patients requiring care themselves and have their needs and concerns addressed by the same team of which they are a part (Sherman, 2019).

Those who feel some control over the situation and have a reliable social support system have more chances of staying physically and psychologically healthy (Rosenthal, 2014). Research shows that healthcare professionals' informational and emotional support benefited caregivers greatly throughout the caring process (Li and Loke, 2013).

Gradually, research, healthcare systems, and healthcare teams understand the critical role family caregivers play in care delivery and work to incorporate them in every step of the care process/treatment (Gillick, 2014), which requires interactions, negotiations, caregiver training, guiding and assistance. As the family caregiver becomes a key member of the healthcare team to achieve patient-centered care, shaping this role through interactions with healthcare professionals becomes critical for their effective performance.

2.2. The family caregiver at the center of the patient-centered approach

Prior studies have shown that collaborative communication between physicians and patients facilitates information exchange and treatment planning, compliance, and satisfaction (Sakai and Carpenter, 2011). They are actors in this encounter who associate and make or promote change with one another (Sayes, 2014).

More recently, the concept of triadic care was developed, and it comprises of the health providers, care recipients, and family caregivers (Morhardt and Spira, 2013). In this arrangement, the family caregiver is another actor who associates with the other two entities to become a triad. Reasons behind these studies are various: change in demographics with a family member caring for a large number of elderly (Kusaba et al., 2016); introduction of enhancements for cooperation and coordination of intra- and extra-mural care to improve standard community care (Vasconcellos-Silva et al., 2007); increasing consultations where the patient is accompanied by another individual (Mazer et al., 2014); the recognition that medical decision-making processes are informed by relationships (Epstein and Street, 2011) and their impact on both the patient and the caregiver (Laidsaar-Powell et al., 2017); the psychological and physical well-being of caregivers during and after caregiving period (Mendes et al., 2011; Linderholm and Friedrichsen, 2010).

Triadic care is guided by relationships and interaction (Morhardt and Spira, 2013). Healthcare professionals, care recipients, and family caregivers interact to combine “technical and trans-disciplinary action schemes” (Vasconcellos-Silva et al., 2007), mix and match lay knowledge, expert knowledge, and action in a shared context. They are potentially participating in “ba”—a shared context where knowledge is shared, created, used, and is related to shared experiences, mental models, and relationships emersion (Nonaka and Konno, 1998).

To understand the triadic care, it is necessary to combine theories that explain collaborative performance, interactions and the associations between humans and non-humans. As of now, there is not one theory that can provide a breakdown of the caregiving activity to the level of family caregiver role shaping and role performance considering the interactions with multiple actors besides the care recipient.

Unlike the ordinary interactions in our daily lives, individuals transcend their barriers and recognize themselves as part of something more significant in the ba. To fully participate or engage in ba means “to get involved and transcend one's limited perspective or boundary” (Towell & Towell, 2001). The present study contends that ba is one’s willingness to give and take, which can occur in informal circles, project teams, e-mail groups, online forums, vacation, and so on (Nonaka & Konno, 1998), bound by space and time. A medical encounter (i.e., consultation) may be an occasion for a ba to emerge in the healthcare scenario.

Weick (1995) explains that people share experiences, which may not lead to shared meaning. These shared experiences, retrospectively analyzed by individuals, rarely have similar meanings; they may, however, be equivalent. The author affirms that people share actions, activities, moments of conversation, and joint tasks.

Epstein and Street (2011) proposed that from the sharing of thoughts, feelings, perceptions, meanings, and intentions among two or more individuals emerges a shared mind, which is both an achievement and an interpersonal process: a process of “becoming attuned” that encompasses the varying degrees of human interaction (Epstein and Street, 2011). Based on this notion of a shared mind, the family caregiver is included in the decision-making processes during caregiving (Laidsaar-Powell et al., 2017).

The idea of becoming attuned aligns with shared context (“ba”), associations, and connections among actors through translations (Latour, 1996). These associations result in different interactions and actions to achieve different results and new shared contexts, resulting in the individuals’ different role socpes in the association, influenced and shaped by these inputs. They resemble activity systems with the subject, object, tools, rules, division of labor, and community (Hasan and Kazlauskas, 2014), which are multi-voice and whose components create different positions for its participants (Engeström, 2004).

It is beneficial to look at the care triad as an activity system because it helps identify the essential elements of caregiving (i.e., subject, object, and tools) while considering the influence of contextual elements (i.e., rules, community, and division of labor). In other words, it articulates that context influences the subject’s response (action), which influences the context (Hardman, 2008).

The caregiver needs to collaborate with the health professional. Tasks are assigned, and certain actions are expected as part of the caregiver role; for a role to be fulfilled, it must be shaped. Interactions between caregivers and healthcare professionals contribute to this shaping process.

2.3. Interactions between the family caregiver and the healthcare professional

Interactions with healthcare providers help build informational and emotional support that will be used by the family caregiver while performing in the caregiver role. It can greatly contribute to an effective performance and a higher sense of control over and preparedness to deal with situations at hand. The shaping of the caregiving role is influenced and can be supported by health professionals.

Research about patients with cancer and their caregivers indicated a need to improve communications between physicians, patients, and caregivers due to a discordance between the patient/caregiver and the oncologist concerning the stage of the disease, treatment goal, and chances of being cured. It is up to the physician to determine if the patients and caregivers clearly understand the status of the disease and the treatment goal (Shin et al., 2018).

As communication affects visit outcomes, such as caregiver satisfaction and instruction retention, physicians are expected to develop ways to assess the caregiver's health literacy and communicate in a manner that will facilitate understanding (Lee et al., 2020).

Despite the evolution in the triadic care concept, a study about the nature of the interaction between physicians, patients, and their companions found that it is often physician-patient interactions and, subsequently, physician-companion interactions where one actor was typically excluded. However, these exchanges promoted a gradual shift from "companion" to "caregiver" when the physician discussed the treatment with the person accompanying the patient. Stating the third person's involvement and acknowledging their input as contributions may transform the situation into a triadic interaction (Neufeld et al., 2012).

An investigation of family caregivers' experience and perceptions of their role showed they: (i) are an unpaid resource to the health system, as many of their tasks are part of caregiving definition, though did not realize that; (ii) see themselves as co-workers, part of the care team, who feel empowered when they share their knowledge and information about the care recipient; (iii) did not see themselves as co-clients and expected help from the care team, though professional acknowledgment and support were key to their well-being; (iv) described themselves as "care coordinators" where they gathered and organized information, and were researchers or problem solvers in deciding upon the best course of action (Law et al., 2021).

Still, reports of family caregivers who feel left out of the decision-making process and medical decisions (Law et al., 2021; Rosenthal et al., 2017) are common. Other reports indicate that family caregivers discussed intensive treatment preferences with a physician only during an acute illness (Dellon et al., 2010). Conversely, a study of medical encounters where a professional interpreter acted as a translator between physicians, patients, and caregivers found that physicians seem to follow communication rules they learned when the exchange happened with the professional interpreter. In contrast, when the interpreter was the family caregiver, these rules did not seem to apply, and physicians could establish partnership grounds (Rosenberg et al., 2007).

The active involvement of the family caregiver role in all treatment steps requires healthcare professionals' involvement in shaping the caregiver role. The integration of the practitioner and their utilization by the healthcare team starts with what the family caregiver’s perceived role encompasses.

Furthermore, for many, settling into a family caregiving role is a process that spans years. The role evolves as care progresses, and studies show that family caregivers are sometimes perceived as partners in care; other times, they are left out of medical decisions. Family caregivers find themselves hopping from one task to another on what is expected from them. These may make shaping the caregiving role a confusing process, influenced, and supported by health professionals.

Chapters 3 and 4 will examine the discussions here and in Chapter 1. Chapter 3 presents a study on the caregiver’s sense of role loss and how it impacts the experience from a role exit and role transitions perspective. Chapter 4 explores the shaping of the family caregiver role through interactions with healthcare professionals from a task and action perspective.

Chapter 3 - A family caregiver’s sense of role loss

Family caregivers reportedly have a powerful sense of role loss when sensing a change in role or responsibility, relationship distancing, or a changed asymmetry. Although many past studies shed light on the family caregivers’ experience regarding identity, condition, illness, or gender, it remains unclear whether caregiving was the primary role and how this variability associates with the reported sense of role loss. This chapter aims to clarify this in three distinct settings: when an individual’s primary role changed to the caregiver role after the start of caregiving; when their primary role differed from the caregiver role after this start; when the primary role was the caregiver role before caregiving began.

Furthermore, little is known about the impact of a family caregiver’s sense of role loss on the experience, its triggers, how it is expressed or manifested, and methods of dealing with the loss. Most studies simply reported the phenomenon with brief mentions of mitigation strategies. In an attempt to fill this gap, this study proposes the following research question:

RQ1: How does a family caregiver’s sense of role loss impact the caregiving experience?

Sixty-six individuals responded to an online survey, and a framework method was employed to organize the collected data and uncover themes for analysis. The findings shed light on the sense of caregiver role loss and indicated its possibility when family caregivers rotate through held roles, using role loss as a tool to maintain or regain a sense of personal choice in life and self-priority.

3.1. Materials and methods

3.1.1. Sample

This study employed the framework method of qualitative data analysis to organize the data and uncover themes (Gale et al., 2013) concerning the sense of role loss and its impact on the caregiving experience. Empirical data were collected through an online survey with Google Forms (Torini, 2016, p. 57) to create a large and standardized sample of data (Sauders et al., 2009, p. 361) without causing much inconvenience to potential respondents; details are provided in Table 2 and Appendix 1. The survey’s overall goal was to capture the family caregivers' experiences through their reflections about the role, their actions in light of the role transition they went through, and the perceived role changes to uncover how a sense of role loss impacted their experience.

Table 2. Details of the online questionnaire

Section	Title	Contents	Objective
0	Caregiver and sense of role loss	A brief explanation about the research, clarification of concepts, and collection of informed consent	To ensure the respondent was aware of the questionnaire's purpose in the context of this study
1	Demographics	Information about gender, duration of caregiving, if the home was shared with the care recipient, if tasks were shared with others, and relationship with the care recipient	To compose a picture of the caregiving context
2	Before caregiving activity started	Respondent to indicate primary, secondary, and tertiary roles (the list of roles presented to the respondents was based on "The Role Checklist" (Oakley et al., 1986) designed to elicit information about an individual's occupational roles, which are: student; worker; volunteer; caregiver; home maintainer; friend; family member; religious participant; hobbyist/amateur; participant in organizations; other) and self-rated performance in each before the start of caregiving activity	To visualize respondents' top three main roles and understand how they perceived their performance
3	After caregiving activity started	Respondent to indicate primary, secondary, and tertiary roles (Ibid.) and self-rated performance in each after the start of caregiving activity	To visualize respondents' top three main roles, understand how they perceived their performance, and see the change in the roles after caregiving started
4	The caregiver	Open-ended questions about what event led the respondent into caregiving, feelings upon becoming a caregiver, what it means to be a caregiver, process of settling in the role, a metaphor or image to describe the role, and checklist of tasks	To give voice to respondents and get a glimpse of their world to understand their experience better

The survey was designed to portray the narrative of caregiving experienced by each caregiver. The respondents were introduced to the concept of sense of role loss, the study and its purpose. This placed them in the exact point in time when caregiving started and the changes it brough to respondents' lives. To avoid limiting their interpretations and answers, no direct question about their sense of role loss was asked to the family caregivers.

The authors reached out to family caregivers' associations through online contact forms, and they contacted acquainted caregivers via e-mail or Whatsapp. A total of 66 individuals responded to the questionnaire. Based on their answers about their primary roles before and after beginning the caregiving activity, three distinct groups of respondents emerged, presented in Table 3.

Table 3. Groups of respondents

Group	Setting	Name and Description	Total (n)
35	The primary role is “caregiver” after the start of caregiving	Those whose primary role changed to the caregiver role after caregiving started	35
27	The primary is other than “caregiver” after the start of caregiving	Those whose primary role did not change to the caregiver role after caregiving started. They either preserved their previous primary role or changed to a role other than a caregiver	27
4	The primary role was “caregiver” before the start of caregiving	Those whose primary role was the caregiver role before caregiving started	4

Before proceeding to the framework analysis, the text of the answers of each group was analysed. By running the text analysis, the aim was to confirm that each caregiving setting generated a different context and, consequently, a different experience. The text analysis would help gain analytical understanding of the groups’ qualitative data (Kwartler, p. 11, 2017) and spot differences in each, aiding the subsequent framework analysis for themes uncovering. Based on the words used by respondents, we would arrive at a high-level view of the experience of each caregiving setting.

At first, only Groups 35 and 27 were contrasted because there was a clearer time when the caregiving activity started. Thus, members of these groups were assumed to have experienced role transition(s), and the family caregiver’s sense of role loss occurred. However, excluding Group 4 from the analysis would be unfair to its members; there is an opportunity to understand these individuals’ role transitions and the sense of role loss they felt, thus enriching the analysis.

The demographics of each group are displayed in Table 4.

Table 4. Demographics of Groups 35, 27, and 4

Group	Event	Gender	Duration of Caregiving	Shares Home	Shares Tasks
35	Illness - 20 (60%) Injury - 7 (20%) Death of in-charge of care - 4 (10%) Disability - 4 (10%)	Female - 28 (80%) Male - 7 (20%)	More than 5 years - 22 (63%) 2–3 years - 4 (11.4%) 3–4 years - 4 (11.4) 4–5 years - 2 (5.7%) Less than 1 year - 1 (2.8%) No longer caregiver - 2 (5.7%)	Yes - 29 (83%) No - 6 (17%)	Yes - 14 (40%) No - 21 (60%)
27	Illness - 15 (56%) Death of in-charge of care - 7 (26%) Disability - 2 (7%) Injury - 2 (7%) Help - 1 (4%)	Female - 20 (74%) Male - 7 (26%)	More than 5 years - 18 (66.7%) 3–4 years - 4 (14.8%) 4–5 years - 2 (7.4%) 1–2 years - 1 (3.7%) Less than 1 year - 1 (3.7%) No longer caregiver - 1 (3.7%)	Yes - 23 (85%) No - 4 (15%)	Yes - 16 (59%) No - 11 (41%)
4	Injury - 2 (50%) Disability - 1 (25%) Illness - 1 (25%)	Female - 4 (100%)	More than 5 years - 4 (100%)	Yes - 4 (100%)	Yes - 1 (25%) No - 3 (75%)

The majority of respondents were women performing in the role for more than five years. Most were led into caregiving in Groups 35 and 27 due to the care recipient's illness. In Group 4, most were led into caregiving due to the care recipient's injury. The majority shared the same home with the care recipient. In Group 27, 59% of respondents shared tasks with others, followed by 40% from Group 35 and 25% in Group 27.

3.1.2. Text analysis

The text analysis was conducted with RStudio Version 1.3.1093 with R version 4.0.3 (2020-10-10). RStudio was chosen because it had a user-friendly interface, it was easy to install the packages used in the text analysis, it is widely used in many fields of research, it is reliable, free, and there are many books and tutorials available to help first-time users learn the R language and use it to run text-analysis exercises. Furthermore, text analysis is well established with R because there is a large collection of packages dedicated to process and analyse texts (Welbers et al., 2017). Please refer to Appendix 2 for the R script.

A text file with the answers for questions 12, 13, 14, 16 and 18[1] for each group. The answers were concatenated in one line, each line represented one answer by a caregiver. Thus, there were three files with 35 lines, 27 lines and 4 lines of text. Each file was analysed individually.

The aim of this analysis was to confirm that each caregiving setting resulted in a different context and experience. To do that, the top 10 most frequent words generated a graph to give an overall view of the context. Because the broad goals of caregiving are shared by majority of family caregivers, we expected the top 10 words to display the same and different words. To further confirm the differences in contexts, the same words that appeared in the groups' top 10 went through a word association analysis that gave us the details of the context around them (Mhatre, 2020).

The words "mother", "care", "caregiver", "caring", "father", "sister", "son","brother", "daughter", "husband", "wife", "duchene", "alzheimers", "alzheimer's", "alzheimer", "autism" were removed from the analysis, because this information was either already in the overall questionnaire or was in other questions of the survey (e.g., relationship with care recipient).

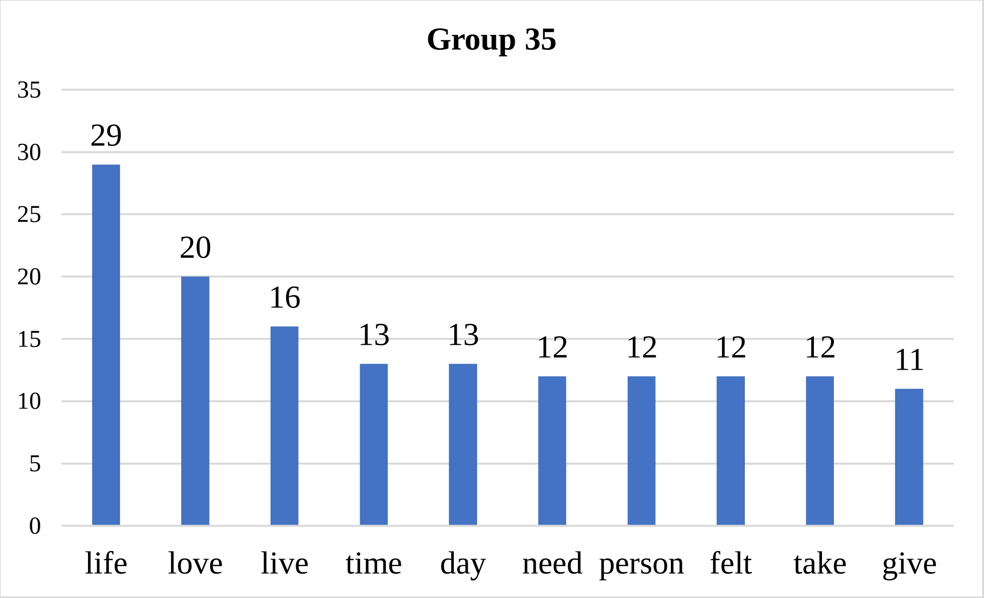

Figure 4. Group 35: top 10 (root) words that occurred more frequently.

Group 35's top 10 most frequent (root) words was populated by words that expressed time (i.e., "time", "day"). About life or living (i.e., "life", "live"), displayed in Figure 4. The

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[1] Questions: 12. What event led you to become a caregiver? (1 to 3 lines); 13. Please describe how you felt when you became a caregiver. (1 to 3 lines); 14. To you, what does it mean to be a caregiver? (1 to 3 lines); 16. Through an image or a metaphor, describe how being a caregiver is. (1 to 5 lines). Examples: "Caregiving is having/being in a story." (Golden et al., 2012). "It is like planning and making all the necessary preparations of a of family trip. And, after boarding the plane, we are suddenly re-routed to another city." (Thomson, 2020); 18. If you can, please describe this process of settling in the role of caregiver. (1 to 5 lines)

root word “need” concerned the needs of the care recipient. “Give” refered to giving the care recipient the best possible care expressed “give him maximum comfort”, “give attention, care and love”. “Person” was used to refer to either the care recipient or something personal to the caregiver.

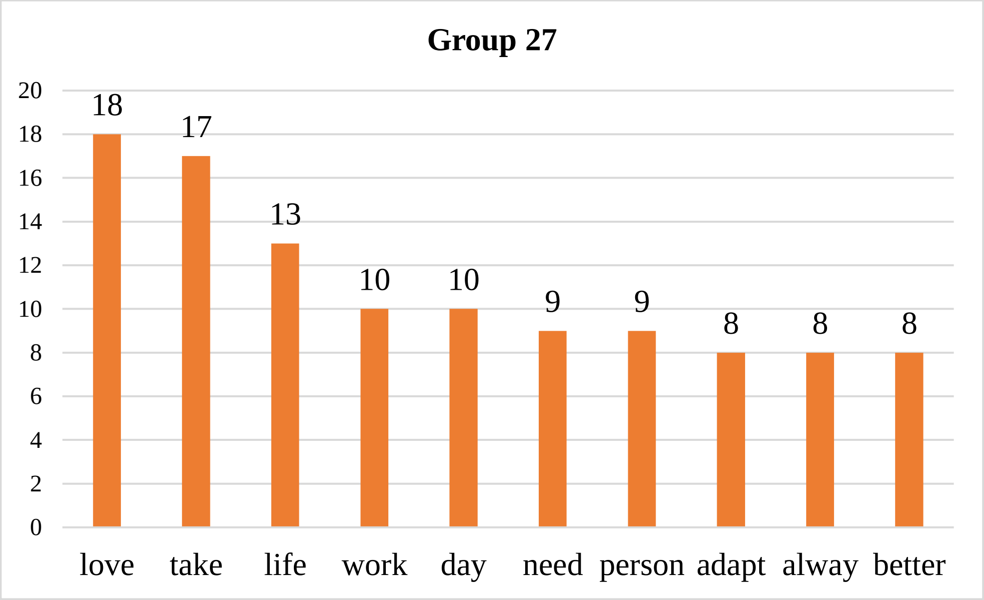

Figure 5. Group 27: top 10 (root) words that occurred more frequently.

Group 27’s top 10 most frequent (root) words expressed time (i.e. “day”, “always”), as shown in Figure 5. In this group, root word “work” appeared in the context of an occupation outside the caregiving activity. The word “need” referred to providing to the needs of the care recipient. “Adapt” was the word used to refer to the process of setting in to the family caregiver role, as explained through “I had to adapt, as we have been married for 50 years, we have always been friends”. Root word “better” was used to explain that a certain situation was better either now or the way it was arranged, such as “I started to understand my son better”, “today is better because I'm always controlling myself” or “In our house he is much better, because whenever he was in continuous care, he was bad”.

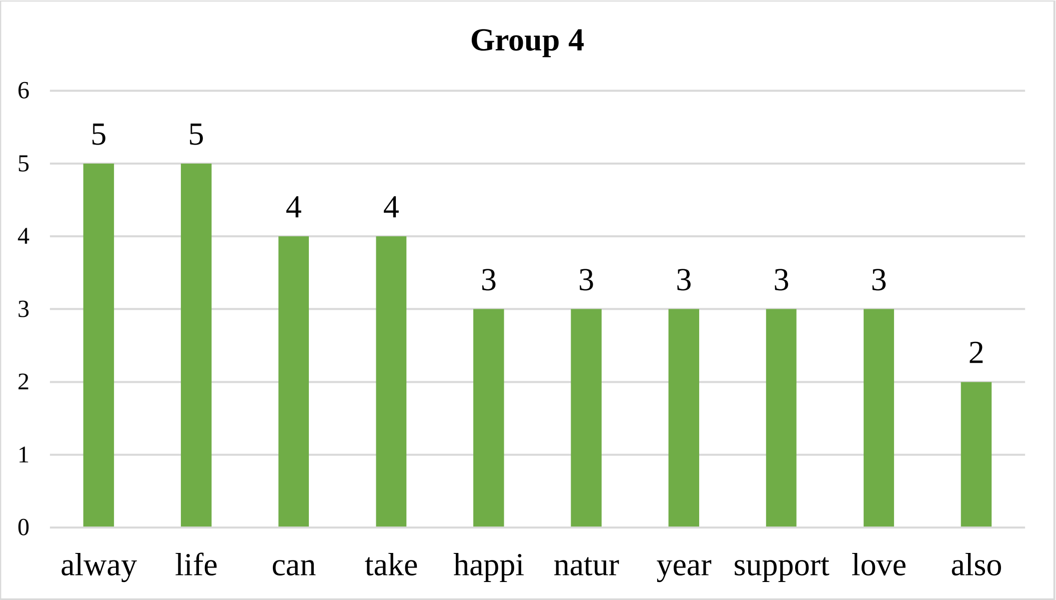

Figure 6. Group 4: top 10 (root) words that occurred more frequently.

Group 4's top 10 most frequent (root) words revealed an interplay of time, life or living and support (i.e., "life", "always", "become", "support"), in Figure 6. Root word "happi" is used in the context of accomplishing a well-being of both care recipient and care recipient (i.e., "I can assure you, either the family has money, or is unhappy" or "always give my sister the best so she can be happy within her limitations", as said by respondents).

The words used in the answers and displayed in the graphs partially confirmed that the caregiving settings differed from one another in general term. Although in different positions, the words "life", "love" and "take" appeared in all top 10s. Thus, to further confirm the settings' differences, correlation (minimum correlation of 0.5, meaning it occured at least 50% of the time with the word) was used to see what words occur most frequently with "life", "love" and "take". This allowed us to see the the context around the repeated words across the groups, as displayed in Table 5, Table 6, Table 7.

Table 5. Associated words with word "Life" (variable $life).

Group 35	**"Life" in the context of lack of choice, possibility to pursue personal activities or working to build the best possible life for care recipient.**										
Associated (root) words	*around*	*began*	*choos*	*chosen*	*circumst*	*citi*	*discov*	*find*	*flourish*	*imagin*	*littl*
	0.77	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*
	locat	*look*	*meaning*	*meant*	*meet*	*neurolog*	*purpos*	*rather*	*reliev*	*rerout*	*say*
	0.77	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*
	serv	*sever*	*thing*	*within*	*yes*	*yet*	*use*	*challeng*	*joy*	*mean*	*choic*
	0.77	*0.77*	*0.77*	*0.77*	*0.77*	*0.77*	*0.69*	*0.65*	*0.65*	*0.63*	*0.56*
	realiz										
	0.55										
Group 27	**"Life" in the context of building the best possible life for care recipient or in the context of a change to caregiver's life and need to make choices.**										
Associated (root) words	*task*	*background*	*christ*	*day*	*degre*	*episod*	*fundament*	*hospit*	*hostag*	*ignor*	*incapacit*
	0.86	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*
	jesus	*left*	*multipl*	*other*	*partial*	*power*	*prioriti*	*promot*	*realiz*	*redefin*	*refer*
	0.8	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*
	replac	*sandal*	*sclerosi*	*social*	*societi*	*supervis*	*turn*	*went*	*accompani*	*disabl*	*perform*
	0.8	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.8*	*0.78*	*0.78*	*0.77*
	put	*patholog*	*prepar*	*attack*	*autonomi*	*mission*	*stimul*				
	0.76	*0.65*	*0.59*	*0.52*	*0.52*	*0.52*	*0.52*				
Group 4	**"Life" in the context of leaving one life's behind, a complete change to caregiver's life, need to learn and maintain quality of life.**										
Associated (root) words	*alway*	*alreadi*	*anymor*	*attend*	*background*	*bath*	*becom*	*behind*	*best*	*born*	*cao*
	0.94	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*
	case	*chang*	*concern*	*constant*	*disabl*	*dress*	*easi*	*enter*	*extens*	*favor*	*gave*
	0.93	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*
	give	*health*	*healthi*	*holiday*	*home*	*institut*	*lack*	*limit*	*live*	*meal*	*natur*
	0.93	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*
	noth	*nowaday*	*other*	*play*	*profound*	*respons*	*rest*	*see*	*sever*	*stay*	*stop*
	0.93	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*

	strong	*tire*	*vacat*	*wait*	*within*	*youngest*	*happi*	*also*	*can*	*diaper*	*difficult*
	0.93	*0.93*	*0.93*	*0.93*	*0.93*	*0.93*	*0.9*	*0.69*	*0.69*	*0.69*	*0.69*
	help	*leav*	*made*	*secur*	*social*	*well*					
	0.69	*0.69*	*0.69*	*0.69*	*0.69*	*0.69*					

Table 6. Associated words with word "Love" (variable $love).

Group 35	**"Love" in the context of the fundamental part of the process of caring and acceptance.**										
Associated (root) words	*accept*	*acquaint*	*demonstr*	*period*	*relat*	*symptom*	*toward*				
	0.57	*0.57*	*0.57*	*0.57*	*0.57*	*0.57*	*0.57*				
Group 27	**"Love" as the foundation of caregiving.**										
Associated (root) words	*year*	*anyth*	*much*	*becom*	*continu*	*psycholog*	*abil*	*afraid*	*alreadi*	*anxious*	*balanc*
	0.67	*0.57*	*0.57*	*0.52*	*0.52*	*0.52*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*
	beauti	*belov*	*brain*	*caus*	*complic*	*deal*	*death*	*descript*	*digest*	*doctor*	*earli*
	0.51	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*
	especi	*etc*	*feed*	*food*	*hard*	*import*	*improv*	*issu*	*lack*	*laughter*	*let*
	0.51	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*
	leukemia	*level*	*long*	*lost*	*maintain*	*mention*	*motor*	*never*	*obstacl*	*part*	*purpos*
	0.51	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*
	qualiti	*selfesteem*	*stabil*	*teach*	*tear*	*term*	*thank*	*tumor*	*uncondit*	*whole*	*woman*
	0.51	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*	*0.51*
Group 4	**Caregiving is "love".**										
Associated (root) words	*accid*	*achiev*	*act*	*everyth*	*fail*	*felt*	*insecur*	*learn*	*level*	*make*	*never*
	1	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*
	new	*stori*	*term*	*thought*	*travel*	*unfortun*	*various*	*way*	*without*	*afraid*	*also*
	1	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*1*	*0.58*	*0.58*
	comfort	*help*									
	0.58	*0.58*									

Table 7. Associated words with word "Take" (variable $take).

Group 35	**"Take" in the context of "take care of care recipient" and full dedication to it with little chances of participation in activities other than that.**										
Associated (root) words	*cage*	*chose*	*enter*	*golden*	*independ*	*key*	*leav*	*outsid*	*suffer*	*throw*	*felt*
	0.68	*0.68*	*0.68*	*0.68*	*0.68*	*0.68*	*0.68*	*0.68*	*0.68*	*0.68*	*0.63*
	away	*social*	*stop*	*home*							
	0.62	*0.62*	*0.61*	*0.55*							
Group 27	**"Take" in the context of "taking care of care recipient".**										
Associated (root) words	*stori*	*anyth*	*friend*	*much*	*bad*	*collabor*	*compani*	*differ*	*easi*	*enough*	*financi*
	0.63	*0.61*	*0.61*	*0.61*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*
	institut	*irrevers*	*just*	*marri*	*moreov*	*pay*	*reform*	*state*	*team*	*technician*	*tell*
	0.54	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*	*0.54*
	truli	*abl*									
	0.54	*0.53*									
Group 4	**"Take" in the context of "taking care of care recipient" and taking a sudden new destination due to caregiving.**										
Associated (root) words	*happi*	*alreadi*	*anymor*	*attend*	*background*	*bath*	*becom*	*behind*	*best*	*born*	*case*
	0.85	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*
	chang	*concern*	*constant*	*disabl*	*dress*	*easi*	*enter*	*extens*	*favor*	*gave*	*give*
	0.82	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*
	health	*healthi*	*holiday*	*home*	*institut*	*lack*	*limit*	*live*	*meal*	*natur*	*noth*
	0.82	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*
	nowaday	*other*	*play*	*profound*	*respons*	*rest*	*see*	*sever*	*stay*	*stop*	*strong*
	0.82	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*
	tire	*vacat*	*wait*	*within*	*year*	*youngest*	*can*	*diaper*	*difficult*	*first*	*leav*
	0.82	*0.82*	*0.82*	*0.82*	*0.82*	*0.82*	*0.71*	*0.71*	*0.71*	*0.71*	*0.71*
	made	*one*	*secur*	*social*	*well*	*alway*					
	0.71	*0.71*	*0.71*	*0.71*	*0.71*	*0.65*					

The words associated with the “life”, “love” and “take” differed in all three groups and their context was different. “Life” and “Take” differed throughout all groups. “Love” had similarities across Groups 35, 27 and 4. Based on this, we could confirm that each caregiving setting had a different context and led to different experiences, so the next step was to analyse the data through framework analysis to uncover themes per groups.

3.1.3. Data analysis

The demographics served to group the respondents and paint an overall picture of each group. Next, the answers to open questions in Section 4[2] were organized into the ERA (Experience–Reflection–Action cycle) (Jasper et al., 2013, pp. 44, 45) and the Reflective Cycle (Gibbs, 1988, pp. 49, 50) frameworks.

There is no reflective practice framework developed specifically to support family caregivers. Therefore, ERA was chosen because it was developed to enable reflective practice in healthcare, and, in this study, family caregivers were conceptualized as practitioners (Hasselkus, 1989) and members of the care team (Sherman, 2019). The Reflective Cycle was employed to break down the analysis of each ERA component and objectively sort the data.

The ERA framework was developed for the nursing practice to help nurses constantly reflect on their experiences and act based on new perspectives generated from this reflection (Jasper, 2003, p. 2). ERA looks at experience, reflection, and action cyclically, where one component feeds the next, allowing individuals to use it as a process tool. ERA is suitable to analyze the respondents’ answers because they are practitioners who reflect on their experiences and act to accomplish goals.

The “Experience” component is what one lives through, or “things that happen to me.” “Reflection” is looking back at what happened to generate new understandings and perspectives. This should result in an “Action,” the application in the practice of what was learned during reflection (Jasper et al., 2013, pp. 44, 45). It was assumed that the experiences shared by the respondents stood out to them in some way (West et al., 2007, p. 38) and therefore were fit for analysis with the framework.

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[2] Open-ended questions in Section 4: 12. What event led you to become a caregiver? (1 to 3 lines); 13. Please describe how you felt when you became a caregiver. (1 to 3 lines); 14. To you, what does it mean to be a caregiver? (1 to 3 lines); 16. Through an image or a metaphor, describe how being a caregiver is. (1 to 5 lines). Examples: "Caregiving is having/being in a story." (Golden et al., 2012). "It is like planning and making all the necessary preparations of a of family trip. And, after boarding the plane, we are suddenly re-routed to another city." (Thomson, 2020); 18. If you can, please describe this process of settling in the role of caregiver. (1 to 5 lines)

Each ERA component was paired with the phases of Gibbs' Reflective Cycle (Gibbs, 1988, p. 61) to achieve granularity in the thematic analysis by posing objective questions to be answered. Throughout the cycle, an individual describes the experience, verbalizes related feelings and thoughts, evaluates and analyses the experience to make sense of it, concludes a learning point or how the experience should have been dealt with, and, lastly, devises an action plan for future similar situations. Each Reflective Cycle phase was answered with their corresponding questions in the survey, as illustrated in Figure 7.

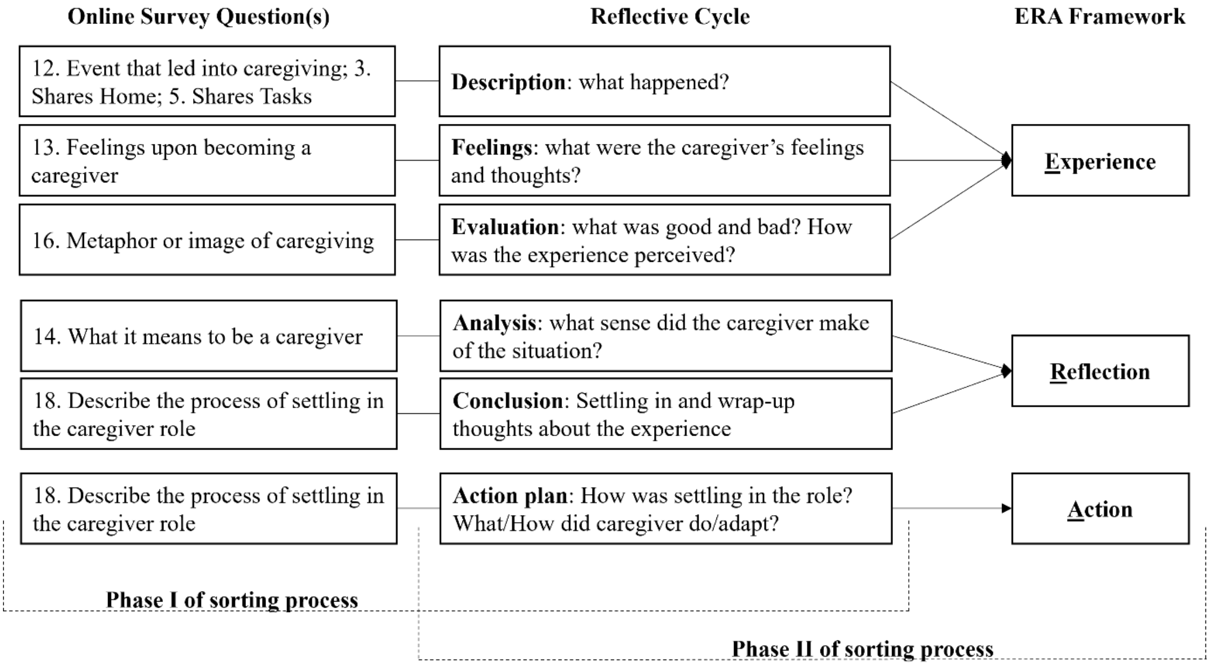


Figure 7. ERA, Reflective Cycle, and survey questions' data-sorting process

The length of the answers to the open-ended questions varied from long reflective paragraphs to one-word responses. As illustrated in Figure 4, these answers went through a two-phase sorting process:

- **Phase I.** Reflective Cycle (description, feelings, evaluation, analysis, conclusion, and action plan) and survey questions
  - **Round 1.** Answers that conveyed the same theme were grouped. Themes emerged from this grouping.
  - **Round 2.** The total number of answers under each theme was summed, resulting in a score.
  - **Round 3.** The themes were ranked from highest to lowest score. Please refer to Appendix 1 for the list.

- **Phase II.** Reflective Cycle and ERA (experience, reflection, and action)
    - **Round 4.** Based on the results of Part I, the themes from description, feelings, and evaluation were combined in experience; themes from analysis and conclusion were combined in reflection; themes from the action plan were carried to action.
    - **Round 5.** The same themes were combined, and their scores were summed.
    - **Round 6.** The top three themes with the highest scores were ranked and selected in the ERA framework, as displayed in Table 8.

Table 8. ERA and the caregiver's experience - consolidated themes and scores

Group	**Experience** **Theme (Score)**	**Reflection** **Theme (Score)**	**Action** **Theme (Score)**
35	TH063 - Focus on the present situation, accepting one does not know what will come in near future, a situation can change quickly. (13)	TH070 - Work for and provide for needs of care recipient anytime; TH071 - Be available and present, always-on mode; TH087 - Care recipient is the priority, dedication. (25)	TH090 - Continuous learning to adapt to changing demands of caregiving while trying to balance personal life. (9)
	TH051 - Worry and anxiety due to a sense of unpreparedness for providing for care recipient's needs, feeling of loss. (11) TH052 - Lack of time and freedom to pursue personal and professional lives, no choice; TH065 - Very low priority put on personal life activities, difficulty planning activities with others. (11)	TH069 - Give up personal choice in life, give up personal life; TH080 - Give up personal life, change to personal life. (9)	TH091 - Support and learning from professionals and associations helped adapt to the role or to be able to pursue personal life activities. (4)
	TH055 - Responsibility, duty; TH067 - Responsibility, duty. (8)	TH073 - Give love and support to the care recipient. (6)	TH089 - Focus on the current situation and attend to it as it requires. (2) TH092 - Responsibility, duty. (2) TH093 - Care became a routine. (2)
27	TH003 - Worry and anxiety due to a sense of unpreparedness for providing for the care recipient's needs. (12)	TH024 - Work for and provide for the needs of the care recipient anytime. (17)	TH044 - Understanding of the care recipient and their condition. (4)
	TH017 - Be present to support and understand the care recipient. (7)	TH027 - Act of love. (6)	TH042 - Determination to face and overcome challenges. (3) TH043 - Learn with and receive support from professionals, associations, attend training. (3) TH046 - Immediate and instinctive settling in the caregiver role and its demands. (3)
	TH019 - Alertness to constantly monitor and adapt to the situation at hand. (5)	TH035 - Difficulty in settling in the caregiver role. (4)	TH041 - Realization that caregiving requires continuous learning. (2)

4	H102 - Lost, alone, lack of support; TH105 - Lack of support, process inefficiencies, paperwork. (4)	TH109 - Work for and provide for the needs of the care recipient anytime, an act of help. (2) TH114 - In the past, easier. Now, more difficult, less energy than when started. (2)	TH117 - Maintenance of/participation in activities/events outside the caregiver role. (1) TH118 - Learn with and receive support from professionals, associations, attend training. (1) TH119 - Left job to focus on care. (1) TH120 - Receive support from a housekeeper. (1)
	TH101 - Worry and anxiety due to a sense of unpreparedness for providing for the care recipient's needs. (2) TH103 - Courage, gratitude, strength from love. (2) TH108 - Unexpected turn of events, a sudden new reality to attend to. (2)	TH110 - Availability. (1) TH111 - Act of love. (1) TH112 - Comforting. (1) TH113 - Exhaustion. (1) TH115 - Difficulty in seeing others 'having a life' when the caregiver is not. (1) TH116 - Had to do what was necessary to support the care recipient/s. (1)	
	TH100 - Caregiving as a natural/anticipated path. (1) TH104 - Give up personal life to prioritize caregiving, being an extension of the care recipient, stop living own life to dedicate to care. (1) TH106 - Resources demanding activity (especially, financially). (1) TH107 - Love. (1)		

The results will be presented in the following section based on these themes.

3.2. Results

3.2.1. Experience

The theme with the highest score in Group 35′s answers reported a need to focus on the present situation, accepting that one could not know what comes next (i.e., TH063). In Group 27, a similar theme ranked third, and it was phrased as a need to be constantly alert and monitor and adapt to the situation (i.e., TH019), but it did not appear in Group 4's answers. This study found that caregiving required a heightened focus on the present circumstance for caregivers to respond quickly to the intense, constantly changing demands of caregiving, which varied among the three settings. Family caregivers found themselves devoting different amounts of time to support care recipients the best way they could. Time, or the lack of it, was a recurrent theme in their answers.

The necessity to focus on a current circumstance impacted the time left for activities outside the caregiver role. This altered the family caregivers' relationship with the past, present, and future times. The alteration of present and future relationships was evident; Group 27 reported a sense of unpreparedness to provide care to the care recipient, with some caregivers mentioning a worry (i.e., TH003) that led to insecurity about what to do now and what the future would hold for both the caregiver and the care recipient. As explained by a respondent:

> *"Despair. As for the future of my son and mine. I was still trying to assert myself professionally; I had a double shift—work and study." (Caregiver 005)*

The same theme was found in Group 35 (i.e., TH051) and Group 4 (i.e., TH101), with similar feelings in respondents, altering their relationships with their present and future times. Additionally, these family caregivers had the relationship with their past altered; they saw a portion of activities they previously carried out or roles they formerly performed as no longer a part of their present lives. They reported little time to pursue personal and professional lives (i.e., TH052), low priority on personal life activities, difficulty planning activities with others (i.e., TH065), and the need to put aside parts of their lives to assist others and be an extension of the care recipient (i.e., TH104).

The need for heightened focus on the present altered the relationship that each group's respondents had with their present and future times. Family caregivers in Groups 35 and 4 indicated that the relationship with their past was altered after beginning the activity.

3.2.2. Reflection

When reflecting on the meaning of caregiving and the process of settling into the caregiver role, all groups stated how crucial their role was in the care recipient's life; they perceived caregiving as work with tasks and goals (i.e., TH070, TH071, TH087, TH024, TH109, TH110) that required being present, availability, dedication, and alertness. It was also about giving love (i.e., TH073, TH027, TH111).

Responses from Groups 35 that revealed changes to respondents' personal lives made it to the top three themes, be it because they felt they gave up personal choice in life or gave up on activities of personal life, in both cases to assist others with their needs and favor their care, as one family caregiver put it:

> *"Caring without schedules, stop having freedom and time for me." (Caregiver 019)*

Group 35 reported they had little chance to pursue personal and professional lives activities due to a lack of time, because of the required availability or the need to prioritize caregiving. The altered relationship with the past time gave rise to a sense of role loss expressed through reflections such as "I stopped having a social life" (Caregiver 007) where the caregiver used to perform in and rotated through roles no longer held, impacting their caregiving experience by contributing to a diminished sense of personal choice and self-priority to assist others with their needs, which is defined in this study as the ability to practice self-priority and pursue one's life activities outside the caregiver role while holding this role.

Group 27′s top three themes differed, but the theme above appeared in Group 4. The difference from Group 35 was that "not having a life" was expressed compared to others "having a life." This was interpreted as a wish to occasionally step out of caregiving, rotate through held roles, and perform as others appeared to be doing. As Caregiver 15 put it:

> *"Being the youngest, I have always lived with her and took care of her. First, I played with her and, naturally, gave her meals, changed her diaper, and, when I was strong, dressed and bathed her, made her meals, so it was easy. Nowadays it is more difficult… I see others having a life, and I don't." (Caregiver 015)*

In Group 27, the respondents either continued to perform the same primary role before the activity started or changed primary roles. In both cases, caregiving was a role they took on or an added feature to an already held one. These individuals continued to rotate through roles;

they exited and entered them regularly and experienced a sense of role loss, particularly caregiver role loss.

The possibility to hold roles outside caregiving and rotate more frequently through them allowed the family caregivers to step out of caregiving from time to time and generate a sense of caregiver role loss that could be used as a tool to maintain or regain a sense of personal choice in life and self-priority. This study defines role rotation as the deliberate act of exiting and entering held roles, occupying, and performing in the salient role of the context, and generating a sense of role loss from the role exited.

3.2.3. Action

Learning, knowledge, and understanding of the care recipient and the condition was the common theme to Groups 35 and 27 (i.e., TH090, TH041). Responses indicated that the caregiving demands might change quickly. All three groups reported the effectiveness of support received from professionals, associations, and training to access knowledge, develop skills, reduce the sense of unpreparedness, improve the quality of the care they provided, and help them balance tasks with the pursuit of personal life activities (i.e., TH091, TH043, TH118, TH120). As Caregiver 024 put it:

> *"In the early years, it was very difficult for me, especially on a psychological/emotional level. Over the years, and thanks to the doctors who accompany my mother, I have been able to 'digest' or deal better with the whole situation. I am aware that future times will become more difficult and complicated, but I will continue to care and love unconditionally." (Caregiver 024)*

In Group 35, caregiving was viewed as a constantly changing process that required continuous learning and focus on the current situation for adaptation (i.e., TH090). This was also found in Group 27, phrased as understanding the situation, having the determination to overcome challenges that appeared along the way, and realizing that the role required learning (i.e., TH044, TH042, TH041). Conversely, a similar theme did not appear in any Group 4 responses.

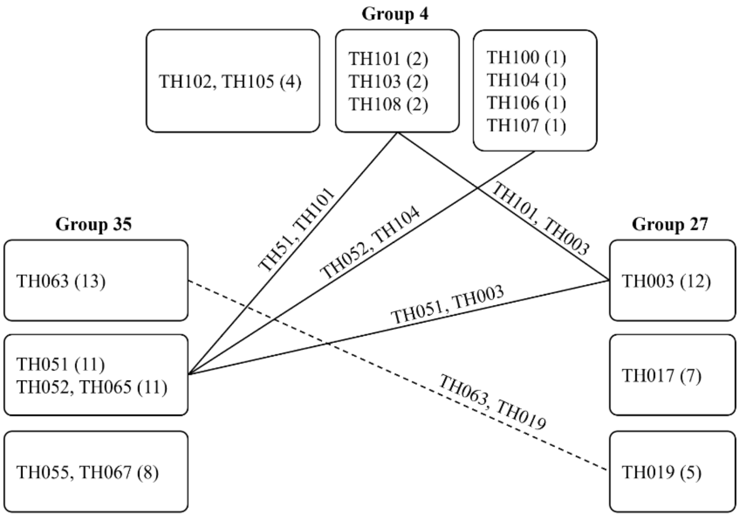
The actions of Groups 35, 27, and 4 pointed to knowledge and learning for suitable adaptation to and performance in the caregiver role. Groups 35 and 27 indicated a need to focus on the present situation. Group 4 revealed the maintenance/participation in activities/events outside the role (i.e., TH117) and a need to leave a job to dedicate to care (i.e., TH119).

Settling into a family caregiver role requires developing ways to deal with the heightened focus on the present situation and mitigate its effect on the caregiver's past, present, future and the development of a sense of preparedness. It enabled the family caregiver to continuously construct the role to either cope with the impact of caregiving had on their lives and to pursue an equilibrium between their role as a caregiver, work, and their personal life.

3.2.4. Network of themes

Based on the previous findings, the group analysis was deepened by understanding how each ERA component's themes relate to caregiving experiences. The same themes across groups were connected by a continuous line representing a strong relationship (1 point). Similar themes and nuances were connected by a dashed line, considered a weak relationship (0.5 points).

A sense of unpreparedness was common to all three groups, as illustrated in Figure 8. Groups 35 and 4 shared the effect caregiving had on pursuing their personal lives’ activities, and Groups 35 and 27 were connected loosely by the need to be alert and monitor the situation.



Connected Themes

TH003 - Worry and anxiety due to a sense of unpreparedness for providing for the care recipient's needs.

TH019 - Alertness to constantly monitor and adapt to the situation at hand.

TH051 - Worry and anxiety due to a sense of unpreparedness for providing for care recipient's needs, feeling of loss.

TH052 - Lack of time and freedom to pursue personal and professional lives, no choice.

TH063 - Focus on the present situation, accepting one does not know what will come in near future, a situation can change quickly.

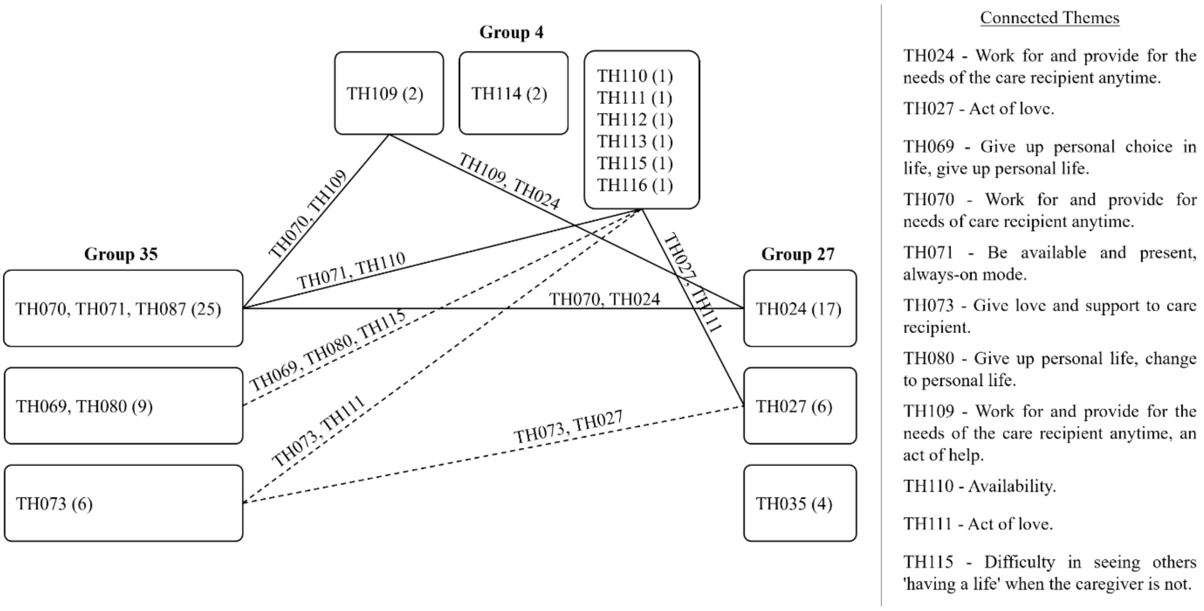
TH065 - Very low priority put on personal life activities, difficulty to plan activities with others.

TH101 - Worry and anxiety due to a sense of unpreparedness for providing to care recipient's needs.

TH104 - Give up personal life to prioritize caregiving, being an extension of the care recipient, stop living own life to dedicate to care.

Figure 8. Network of themes in experience

The themes in reflection composed the densest network of all, as Figure 9 shows. It revealed a myriad of interpretations with strong and weak connections between groups whose members perceived caregiving as work focusing on and prioritizing the care recipient. All three groups also viewed the caregiver role as either an act of love or providing love and support to the care recipient. Groups 35 and 4 related when they verbally expressed the effect caregiving had on their personal lives and how it demanded availability.



Connected Themes

TH024 - Work for and provide for the needs of the care recipient anytime.

TH027 - Act of love.

TH069 - Give up personal choice in life, give up personal life.

TH070 - Work for and provide for needs of care recipient anytime.

TH071 - Be available and present, always-on mode.

TH073 - Give love and support to care recipient.

TH080 - Give up personal life, change to personal life.

TH109 - Work for and provide for the needs of the care recipient anytime, an act of help.

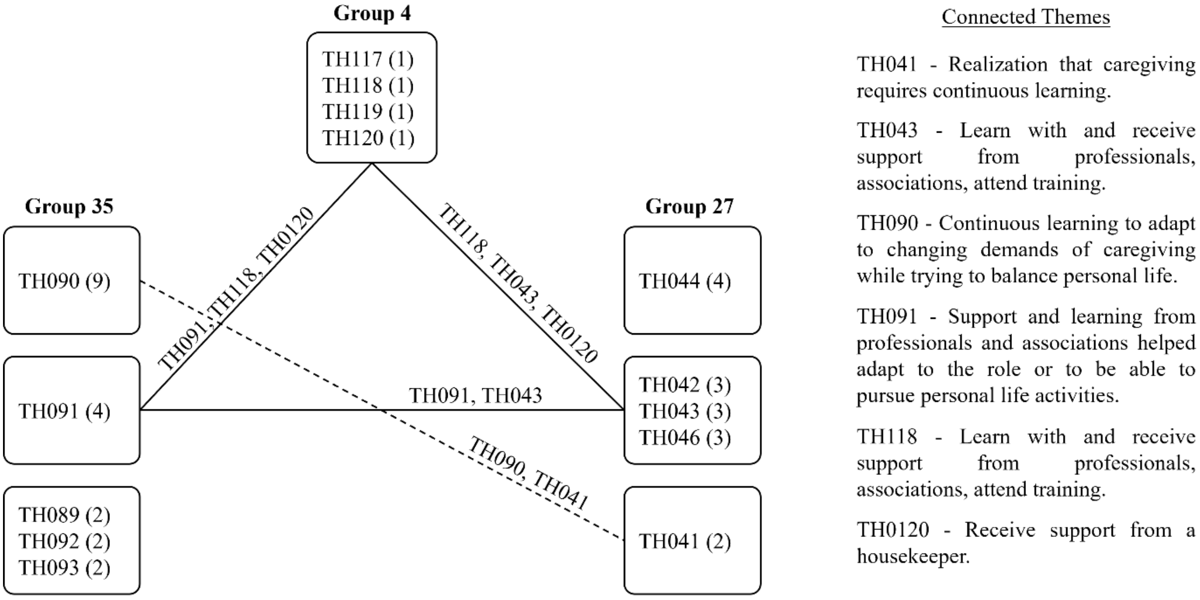
TH110 - Availability.

TH111 - Act of love.

TH115 - Difficulty in seeing others 'having a life' when the caregiver is not.

Figure 9. Network of themes in reflection

Caregiving is far from an easy activity. Settling into the role and managing its changes requires different strategies suitable to the various experiences. The network of themes in action showed the three groups acknowledged the positive impact of the support received from professionals (i.e., healthcare, housekeeper), associations, and training to acquire skills and build confidence, as illustrated in Figure 10. Groups 34 and 27 shared the necessity of continuous learning as caregiving progressed and its demands changed.



Connected Themes

TH041 - Realization that caregiving requires continuous learning.

TH043 - Learn with and receive support from professionals, associations, attend training.

TH090 - Continuous learning to adapt to changing demands of caregiving while trying to balance personal life.

TH091 - Support and learning from professionals and associations helped adapt to the role or to be able to pursue personal life activities.

TH118 - Learn with and receive support from professionals, associations, attend training.

TH0120 - Receive support from a housekeeper.

Figure 10. Network of themes in action

Based on the three networks, it was possible to calculate the strength of relationships among the three groups' experiences based on the scores of continuous and dashed lines connecting the groups. The scores enable viewing how strongly each group's experience relates to the other, as displayed in Figure 11.

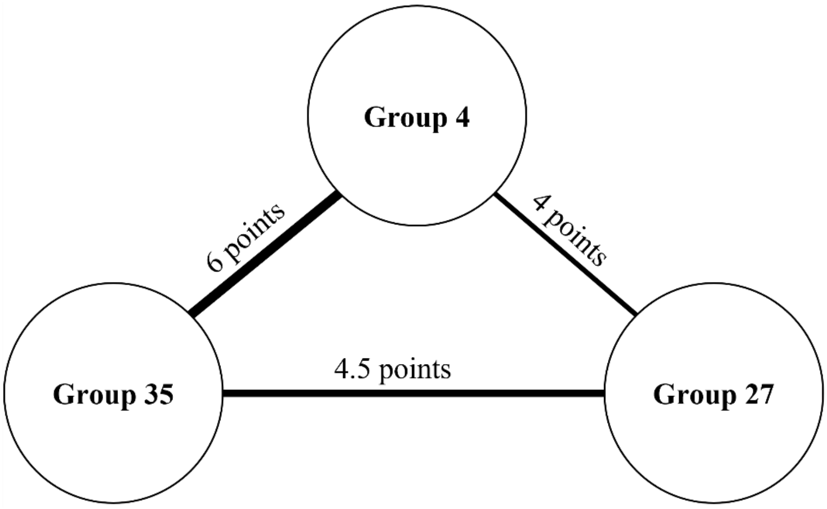


Figure 11. Diagram of groups' experiences and strength of relationships

Groups 35 and 4 scored the highest number of the same or similar themes in their experience. Surprisingly, these two groups felt a sense of role loss and impacted their experience. Group 4's transition into the caregiver role was expected to be the most gradual since they reported they were caregivers before the activity started. These two groups expressed a lower priority for pursuing personal life activities than assisting the care recipient and attending to caregiving demands, combined with a sensed lack of personal choice in life and self-priority. Group 4 also mentioned this perspective comparatively (e.g., "difficult to see others living their lives while they are not").

The relation of experiences between Groups 35 and 27 had the second-highest score, whereas the weakest relationship was between Groups 27 and 4. Given these results, Group 27's experience related the least to other groups, suggesting that the sense of role loss impacted their caregiving experience differently.

3.3. Discussion

This study aimed at understanding how the caregiver's sense of role loss impacted the caregiving experience regarding "primary role transformed" caregivers (those in Group 35 and whose primary role was the caregiver role after caregiving started), "primary role preserved" caregivers (members of Group 27 and whose primary role was other than the caregiver role after the start of the activity), and "constant" caregivers (respondents in Group 4 and whose primary role was the caregiver role before caregiving started). Addressing this variability in the caregiving settings sheds light on how the sense of role loss differed per group and, consequently, how it impacted the experience.

The first finding was that caregiving required caregivers to focus on the present situation to respond quickly to its changing demands and varied among the groups. This altered the respondents' relationship with their present and future. In the case of primary-role-transformed and constant caregivers, their past relationship was also changed. Uncertainty for the future (Hasselkus, 1988; Shilling et al., 2017) and an inability to plan (Shilling et al., 2017) or live in the present were recurrent themes for these individuals. An imbalance between caregiving, the caregiver’s personal life, and efforts to balance the two (Ebadi et al., 2018) was expressed as “no time for personal life,” which did not make it to the top recurrent themes of primary-role-preserved caregivers.

The altered relationship with the past and the transformed primary role gave rise to a perception of life before caregiving that could not be lived at that moment. Constant caregivers expressed similar feelings and compared them with other people “having a life.” The necessity to be available and alert to the current situation hindered the caregiver’s ability to plan personal and professional activities they previously joined or hoped to join. This led to macro role transitions with permanent exits from roles due to this life transition. Primary-role-preserved caregivers took on the caregiver role and either maintained their primary role or changed it to a role other than caregiver; they kept going through micro role transitions by rotating roles and performing in them.

The second result showed that primary-role-transformed and constant caregivers have an altered past relationship and experience permanent exits from past roles. This gave rise to a sense of role loss that impacted their caregiving experience by contributing to a diminished sense of personal choice and self-priority in the caring process. A sense of role loss is part of the caregiving experience, it arises from it and, also, affects it back. These caregivers prioritized assisting others with their needs and perceived they could no longer perform in past roles. Prior studies found that those who felt obligated to assume the caregiver role were three times more likely to report stress (Winter et al., 2010), with perceived lack of choice associated with higher emotional stress, physical strain, and negative impacts on health (Schulz et al., 2012). In contrast, a sense of free choice in entering the role positively affects the family caregiver’s well-being (Al-Janabi et al., 2018).

These past studies focused on the choice of caregiving before assuming the role and the caregiver’s well-being during the activity, not on the choice of entry into other roles while providing care. In addition, it is not uncommon that individuals have little or no choice but to become family caregivers. The concept of choice during the activity may take different, `unforeseen shapes. The present study advances this knowledge by understanding the dynamic interplay among role rotation, sense of (caregiver) role loss, and sense of personal choice in life and self-priority during caregiving, not before it.

Primary-role-preserved caregivers took on this role or added its features to an already held one. These individuals carried on with other roles, transited through them, and feeling temporary senses of role loss; however, their reports did not suggest a diminished sense of personal choice in life and self-priority. Research shows that family caregivers performing in the marital and employment roles reported better psychological and physical health (Barnett, 2015). Those caring for someone with a mental disability experienced fewer stress outcomes as they spent more hours outside work (Bainbridge et al., 2006). It was concluded that these individuals experienced a sense of caregiver role loss by occasionally stepping away from caregiving.

It can be argued that the possibility to hold and rotate through different roles helps caregivers expand capabilities to promote activities and lifestyles they value and flourish within the circumstances at hand (Thomson, 2014, location no. 444, 453). Role rotation helps generate a sense of caregiver role loss that can be a tool to equalize family caregivers’ freedom of functioning (Kittay, 2019, p. 139), maintain a sense of personal choice in life and self-priority, and perform in this role.

Third, focus on the current situation and possession of knowledge and skills were mechanisms employed by family caregivers to deal with issues at hand, with support from professionals and associations. This finding aligns with prior studies indicating that preparedness was associated with caregivers’ higher levels of hope and reward, lower levels of anxiety (Henriksson and Årestedt, 2013), and the need for knowledge and learning (Fernandes and Angelo, 2016). Additionally, preparedness helped caregivers maintain or regain a sense of control over their relationships with the past, present, and future by generating a context where they could create new meanings and narratives about their own care experiences.

The findings allowed to identify role rotation, the sense of caregiver role loss, and the sense of personal choice in life and self-priority as components of the caregiving experience, understand their interplay and see their impact back on this experience, as illustrated in Figure 12. Each may be looked at as sub-experiences that can happen, and compose the overall scope of the caregiving experience among others not covered in this study.

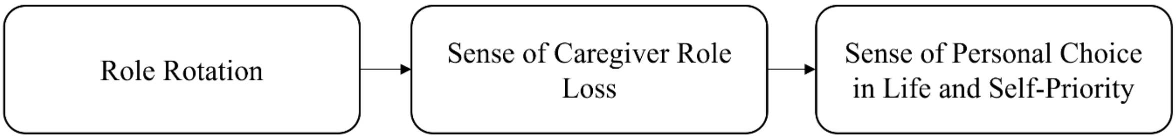


Figure 12. Role rotation, sense of caregiver role loss, and sense of personal choice in life and self-priority

This relationship aids understanding why the experience of primary-role-transformed and constant caregivers is related more often. According to their answers, the respondents had fewer possibilities to rotate through held roles, step out of caregiving, generate a sense of caregiver role loss, and increase or regain a sense of personal choice in life and self-priority. Primary-role-preserved caregivers took on this role, kept rotating through others, and generated a sense of caregiver role loss that contributed to maintaining their sense of personal choice in life and self-priority.

Practical implications are presented to family caregivers and the support system (i.e., healthcare professionals, enterprises, associations, governments). They are consolidated in Table 9 and Table 10, respectively, and contain excerpts of family caregivers' responses to demonstrate how they managed their caregiving experiences.

Table 9. Practical implications to the family caregiver

Implication	**Excerpt**
Try to look for or assign new meanings in personal activities.	*"I think there was a moment after around 5 years of giving total care that I realized nothing was going to change. That I had to find peace and joy in the life I was living. So, I began to look around for ways to locate purpose and meaning in my life. And I did—these were very little things, but they were meaningful to me." (Caregiver 001*)
Try to step out of the caregiver role by attending social events, spas, and such.	*"And I manage to do spas three times a year, to maintain my quality of life (...) I go to the music concerts, and to the mass, so that God may bless and protect us." (Caregiver 020)*
Try to look at caregiving as a dynamic activity that requires continuous learning and adaptation; if possible, attend training.	*"Learning and continuous adaptation. Try to maintain mental and physical balance and thus be possible to balance in the other dimensions of our life (social, family, professional)." (Caregiver 038)* *"I felt prepared, I attended training before, it was an opportunity to be with my mother, which had not happened since I started working." (Caregiver 052)*
Reach out to healthcare professionals and voice out the concerns.	*"I read a lot, I talked to doctors and nurses. It is difficult, but I can perform with courage and gratitude. I had to leave my job to take care of them." (Caregiver 020)*

Table 10. Practical implications to the support system

Support System	Implication	Excerpt
Healthcare professionals	Communicate with family members and clarify who the caregiver is. Ensure the title is given to this person and explain the role's demands.	*"I did not realize what was happening because nobody tells the caregiver that he became a caregiver… they tell the patient that he is sick… we assume the role, and that's it. As I didn't have time to prepare, I felt outdated." (Caregiver 030)*
	Be approachable so that caregivers can reach out and listen to their concerns. Offer support and guidance in the process. Help them prepare for future demands and decisions to be made.	*"Over the years, and thanks to the doctors who accompany my mother, I have been able to 'digest' or deal better with the whole situation. I am aware that future times will become more difficult and complicated, but I will continue to care and love." (Caregiver 024)* *"In the beginning, my son had many tantrum attacks. It was a painful process, but with therapies and my participation in training courses on autism, I started to understand my son better." (Caregiver 005)*
Associations	Continue and increase the range of initiatives to ensure caregivers have a community they can count on. Help employee–caregivers and enterprises communicate and build caregiver-friendly working cultures.	*"We become caregivers—keyword 'we become' which presupposes progress. It is not a static process; it's dynamic, constantly evolving because we must constantly adapt to the progress of illness and the needs of the person being cared for. The association's support is fantastic in this exercise: we are less adrift!" (Caregiver 030)*
Enterprises	Understand the employee–caregiver need for a flexible schedule and work opportunities. Together, work on concrete solutions to ensure their well-being and proper performance in both and more roles.	*"I changed my whole life. I negotiated schedules with the employer, adapted the house to the best of my ability, and put aside my usual routines. Going out on weekends and socializing with friends has become the last priority, being possible only with the collaboration of third parties." (Caregiver 064)*
Governments	Work out programs to financially support and facilitate access to home care and house adaptation services. Promote initiatives that help enterprises build caregiver-friendly working cultures. Support associations to increase their initiatives targeting caregivers and enterprises.	*"Outraged by the state's lack of support (I don't mean financial) to have time to breathe, rest, sleep and reconcile with employment." (Caregiver 032)* *"I made an effort, so that they were well and happy, during the day I had the support of a housekeeper." (Caregiver 020)* *"(I) adapted the house to the best of my ability." (Caregiver 064)*

On a theoretical level, this research contributes to caregiving knowledge and how the sense of role loss impacts the caregiver's experience. Prior studies identified and defined this feeling and portrayed contexts where it was felt. This study delved into the caregiver's sense of role loss, uncovered its impact on the caregiving experience, shed light on the sense of caregiver role loss, and pointed to possible role loss when these individuals rotated through held roles. Role rotation allows family caregivers to step out of caregiving from time to time, and the sense of caregiver role loss can be a tool to maintain or regain a sense of personal choice in life and self-priority. Table 11 displays our contribution by consolidating it with the existing body of studies about sense of role loss presented in Table 1.

Table 11. Studies about the sense of role loss updated with our contribution.

Study	When It Is Felt	By Whom	Cause/s	Impact on experience	Mitigation
Hasselkus (1988)	Throughout caregiving	Family caregiver	Change in role and responsibility; Relationship distancing or a changed asymmetry		
Dellasega et al. (1995)	After the care recipient's placement in a nursing home	Family caregiver	Nursing home placement		Redefinition of the caregiver role (expressed longing to resume prior roles)
Kellett (1998)	After the care recipient's placement in a nursing home	Family caregiver	Sensed change in engaged involvement		Finding new ways of caring for the relative
Kim and Moen (2002)	Upon and after retirement	Retiree	Exiting role central to identity and environmental loss accompanying the role exit		
Williams (2014, p. 106)	Foster child arrival at or departure from the family	Birth Children	Place or position constant re-alignment to accommodate a foster child		
Tummala-Narra and Deshpande (2018, p. 175)	Post-immigration	Immigrant	When shifts in power, respect, and authority within the families occur		
Ribeiro, Ho, Senoo (2021)	While carrying out the caregiving activity	Family caregiver	Permanent exit from past roles to focus on caregiving, be present and prioritize assist	Diminished sense of personal choice in life and self-priority	Role rotation can help generate sense of caregiver role loss. Information and knowledge increases sense of preparedness, control over situation

Most studies reported this phenomenon, but few mentioned mitigation strategies for the negative effects. This study was motivated to explore the phenomenon more deeply to understand how it affects caregivers and better support them through the seemingly inevitable role loss. Additionally, this study examines three different caregiving settings based on their primary role and role transition. Then, the experience of primary-role-transformed, primary-role-maintained, and constant caregivers was contrasted. This study can contribute these additional settings to prior studies, which accounted for identity, condition, illness, and gender. The motivation behind looking at different settings was to account for variability, provide different perspectives, and see the multiple faces of the sense of role loss.

One limitation of this study is the sample size of constant caregivers (Group 4). Despite respondents' rich input, more answers would have provided more insights about their experiences. The data analysis did not consider the caregiving duration, gender, sharing of tasks, or how they contribute to using a sense of role loss as a tool. Furthermore, this study looked at the sense of role loss as a one-time-only phenomenon; however, it could be multi-faceted and occur multiple times as care demands change, so it will be useful to understand its stages and characteristics. Future studies could address these limitations to help advance the knowledge about caregiving and effectively support a wider range of caregivers.

Caregiving is rarely easy or smooth. Family caregivers are a unique type of practitioner because the role emerges from existing relationships (Montgomery & Kosloski, 2009). Thoroughly understanding the phenomenon of the sense of role loss can uncover new ways of improving the caregiver's experience regarding the burden, stress, quality of care, and overall well-being of caregivers and care recipients.

3.4. Conclusion

This chapter aimed to understand how a family caregiver's sense of role loss impacts a family caregiver's caregiving experience. The data for analysis were collected through an online survey answered by 66 individuals. Text analysis to gain to contrast groups context and gain a high-level analytical understanding of each was conducted. Then, the framework method was employed to organize the data into themes for analysis. The findings shed light on the sense of caregiver role loss and indicated its possible occurrence when individuals rotate through held roles. Role rotation allows family caregivers to step out of caregiving from time to time; the sense of caregiver role loss can be a tool to maintain or regain a sense of personal choice in life and self-priority.

The findings indicate the importance of healthcare professionals' support during the caregiving activity, and the next chapter explores how the caregiver role is shaped through and influenced by interactions with the healthcare professional.

Chapter 4 - Shaping the family caregiver role through interactions with the healthcare professional

Chapter 3 revealed that family caregivers acknowledged the positive impact of the support from professionals (i.e., healthcare, housekeeper), associations, and training to acquire skills and build confidence. However, they may sometimes feel excluded from medical decisions, be confronted with unrealistic expectations, or receive comments about their ability to perform in the role, which affects them negatively (Law et al., 2021).

The active involvement of the family caregiver role in all treatment steps requires healthcare professionals' involvement in shaping the caregiver role. The integration of the practitioner and their utilization by the healthcare team starts with what the family caregiver role encompasses.

Furthermore, for many, being a caregiver and settling in this role is a process that spans years. Interactions with healthcare providers help build informational and emotional support that will be used by the family caregiver while performing in the caregiver role. It can greatly contribute to an effective performance and a higher sense of control over and preparedness to deal with situations at hand.

Healthcare professionals may support the shaping of the role through gradual teaching, guiding, and assignment of tasks. However, little is known how interactions with these professionals influence the shaping of the family caregiver role from a tasks and actions perspective. This study aims to gain understanding through the following research question:

RQ2: How is the family caregiver role shaped through interactions between the family caregiver and the healthcare professional?

Eight healthcare professionals and 12 family caregivers answered an online survey. Data was interpreted through hermeneutic analysis; the framework method was applied to sort out humans and non-humans and clarify their associations and expected tasks and actions (the division of labor). Text-analysis was conducted to contrast answers.

The findings suggested that interactions with the healthcare professional provide the family caregiver role with a pre-defined shape. There were fixed tasks, actions, and the family caregiver was expected to behave according to expectations. There was little room for reflection or negotiation. The shared information or knowledge was limited to these fixed tasks and expected actions.

When the interaction was with the care recipient, the daily demands of caregiving and the dyadic structure of the care recipient-family caregiver relationship imposed constant negotiation and transformation of tasks and actions so that the role continued to be relevant. With this, the family caregiver could continue providing the most suitable and customized care to the care recipient. This care was based on the circumstance at hand. The list of tasks and actions was often revised and renewed, and the shaping of the role is a continuous process.

4.1. Materials and methods

4.1.1. Sample

For the empirical collection of qualitative data, one questionnaire was prepared for family caregivers and another for healthcare professionals. The questions were essentially the same but phrased according to the targeted group of respondents. The objective was to collect answers from two different perspectives to complete a view of the shaping of the family caregiver role through interactions between caregivers and healthcare professionals while simultaneously contrasting the two perspectives.

The questionnaire ensured the interactions were the primary focus by asking the respondents to keep a medical consultation in mind while answering. This study assumed the consultation to be an event with high chances for interactions. It was considered a ‘ba’ that served as the foundation for knowledge creation, related to shared experiences, mental models, spaces where relationships emerge (Nonaka et al., 1998), and the participants became attuned (Epstein and Street, 2011).

Google Forms (Torini, 2016, p. 57) was used for easier diffusion and respondents’ comfort as they could answer remotely through their phones or computers. Both questionnaires explained the study to potential respondents. The questionnaire directed at caregivers had seven questions (one multiple choice and six open-ended), and respondents were encouraged to share their thoughts freely. The questionnaire directed at healthcare professionals had eight questions (one multiple choice and seven open-ended) where respondents were encouraged to share their thoughts freely. The structure of each is presented in Table 12.

Table 12. Questionnaires for caregivers and health professionals

Scenario for family caregiver: Think of when you accompany a patient (i.e., family member, partner) as a caregiver to a consultation. Please try to recall how such consultations usually go and answer freely the following questions.

Scenario for healthcare professional: Think of when a patient comes for a consultation and the caregiver accompanies him/her. Please try to recall how such consultations usually go and answer freely the following questions.

Objective	**Questions for Caregivers**	**Questions for Healthcare Professionals**
Identifying and associations in the course of the treatment; Elucidating the (expected) tasks and actions by the actors.	1. For majority of the cases, whose voice do you feel is prioritized by the healthcare professional? a) Voice of the patient b) Voice of the caregiver	1. For majority of the cases, do you prioritize the voice of the patient or the voice of the caregiver? a) Patient b) Caregiver
	2. Please share with us situations you feel the voice of patient is prioritized.	2. Please share with us situations when the voice of patient is prioritized.
	3. Please share with us situations you feel the voice of caregiver is prioritized.	3. Please share with us situations when the voice of caregiver is prioritized.
Elucidating the (expected) tasks and actions by the actors; knowledge creation experiences.	4. How do you think the healthcare professional involves the patient in the treatment (role in treatment) and what actions do you think he usually expects from patient?	4. How do you involve the patient in the treatment (role in treatment) and what actions do you usually expect from him/her during treatment?
	5. How do you think the healthcare professional involves the caregiver in the treatment (role in treatment) and what actions do you think he usually expects from caregiver?	5. How do you involve the caregiver in the treatment and what actions (role in treatment) do you usually expect from him/her during treatment?
	6. Now, think of the treatment in its entirety (first and subsequence consultations). How do you see the information and knowledge shared by patient and caregiver throughout treatment to be utilized by healthcare professional in practical terms?	6. Now, think of the treatment in its entirety (first and subsequence consultations). How do you utilize the information and knowledge shared by patient and caregiver throughout treatment in practical terms?
Demographics	7. Country	7. Country
		8. Profession

The questions concerned the patients and the caregivers because they unite in a dyad; it was assumed that the questions were necessary to study the caregiving role shaping. Questions 1, 2, and 3 were used to identify the actors and understand the agency to determine how the role takes shape throughout the treatment. Questions 4, 5, and 6 targeted elucidating the (expected) tasks and actions. All questions were expected to uncover knowledge creation experiences. Question 6 was expected to reveal applications of this knowledge back into the patient's treatment. Questions 7 and 8 established the respondents' demographics. Please refer to Appendix 3 and 4 for the entire survey.

The open-ended questions were used to the respondents' a voice and provided a window to their context. The questionnaires were sent via Whatsapp and e-mail to family caregivers and healthcare professionals acquainted with the author. The respondents kindly forwarded the relevant URL to their peers.

The analysis obtained answers from family caregivers and healthcare professionals. First, hermeneutic analysis and interpretation (Linderholm and Friedrichsen, 2010) were used to uncover their practices by focusing on each group of responses. The framework method (Gale et al., 2013) was then employed to sort out humans and non-humans and clarify their associations. Text-mining was conducted to generate diagrams to help analyze (Aggarwal and Zhai, 2012, p. 2) and contrast answers about the caregiver role shaping through interactions.

4.1.2. Data analysis

The answers were collected from 12 family caregivers and eight healthcare professionals in Japan, Singapore, and Brazil. Despite the nationality of respondents and potential cultural differences, the study did not intend to analyze and contrast these differences. Rather, use the diverse pool of answers to enrich the analysis of commonalities.

The answers were translated to English. First, the answers were translated with Google Translate to streamline this process. Then, each answer was checked by the researcher to ensure that the tool had captured the correct gender, nuances of the language and metaphorical expressions. These answers were originally in the researcher's mother tongue.

All healthcare professionals were physicians from varied specialties, hereafter referred to as physicians. The phases of analysis aimed to:

1. Separate servers, customers, and technology (i.e., non-humans) to sort out the potential associations through Froehle and Roth's (2004) Modes of Customer Contact with Technology framework.
2. Identify actors and associations in the course of the treatment to understand the caregiver's agency in role shaping.
3. Perform a text analysis to generate co-occurrence networks of words from answers of caregivers and physicians for each of the questions. Then, contrast these networks to clarify the processes of caregiver role shaping through interactions of these respondents.

4. Conceptualize the associations as activity systems to understand the inner dynamics so that implemented tasks and actions and those expected to be executed could clarify the system's division of labor and inner dynamics.

4.3. Results

4.3.1. Analysis 1: sorting servers, customers, and technology

This study conducted an overall analysis of the answers to all questions to create a visual representation of servers, clients, and technology with Froehle and Roth's (2004) Modes of Customer Contact with Technology framework (Figure 13). It ensured humans and non-humans were sorted out and determined where each was placed in the consultation encounter. In this framework, the authors categorized customer contact into face-to-face and face-to-screen interactions. Within each, they identified technology placements in a service encounter based on its role in providing the service.

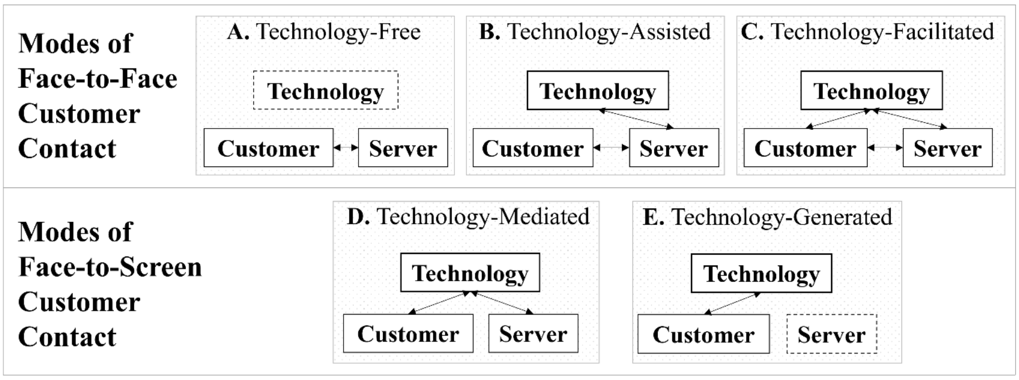


Figure 13. Role of technology in service encounter (Froehle and Roth, 2004)

It was assumed that the consultation would occur in a physical location, so it was categorized as a face-to-face mode of contact (pre-COVID-19). In this case, the patient, physician, and caregiver encounter qualified as technology-assisted contact, shown in Figure 10. Both had face-to-face contact with the patient, employing the technology to improve this contact (Froehle and Roth's, 2004). Physicians and caregivers qualified as servers who provided the caregiving service to the patient. The patient was the client (i.e., the service recipient) served with the provided care.

The technology that respondents mentioned were health assessment questionnaires, shower chairs, and information systems for recording information and sharing information with a wider community of experts. While community with experts was mentioned, it stayed in the background of the encounter, as displayed in Figure 14. Servers used technology as a tool to either collect and share information or to accomplish a task.

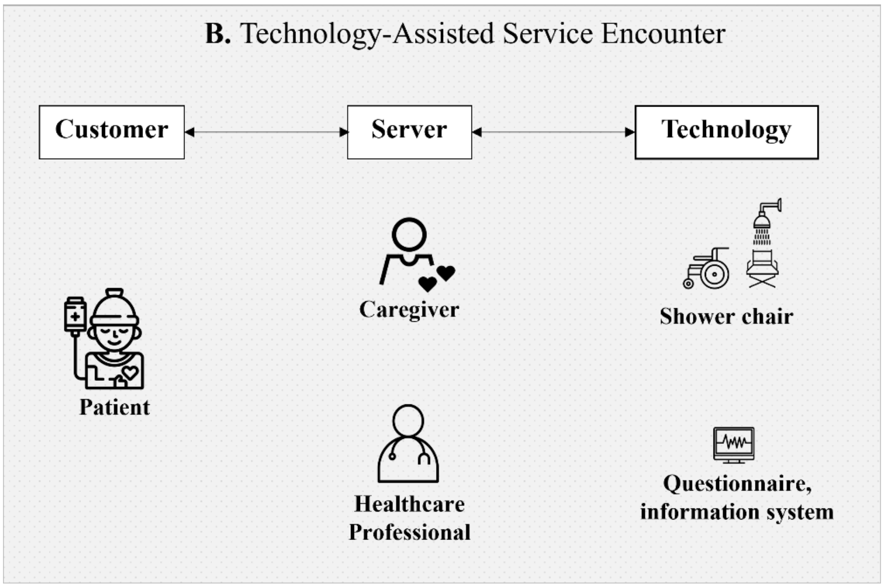


Figure 14. Technology-assisted customer contact

The patient was placed at one end of the encounter and did not have technology as a tool. With servers, client, and technology placements crystallized, the next analysis revealed actors and associations to clarify the family caregiver's agency.

4.3.2. Analysis 2: clarifying actors and associations

Analysis 2 utilized the answers to questions 1, 2, and 3[3]. All eight physicians informed they prioritized the patient's voice. Seven family caregivers informed the patient's voice was prioritized, and the remaining said the caregiver's voice was prioritized. The patient was the physicians' preferred primary source of information to communicate their condition and explain the problem and the current physical state. As one physician put it:

> *"When the patient is lucid, oriented, and able to explain very well what he or she feels."*

An actor is a source of action; this source may be human or non-human, has agency, can only act in combination with other actors (Cresswell et al., 2010), and makes or promotes a difference in another entity or network (Sayes, 2014). Agency is described as the capacity to

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[3] (Caregivers) 1. For majority of the cases, whose voice do you feel is prioritized by the healthcare professional? a) Voice of the patient or b) Voice of the caregiver; 2. Please share with us situations you feel the voice of patient is prioritized. 3. Please share with us situations you feel the voice of caregiver is prioritized.
(Healthcare Professionals) 1. For majority of the cases, do you prioritize the voice of the patient or the voice of the caregiver? a) Patient or b) Caregiver; 2. Please share with us situations when the voice of patient is prioritized.; 3. Please share with us situations when the voice of caregiver is prioritized.

act, to matter (Dolwick, 2009) and requires negotiation in every interaction (Young et al., 2017).

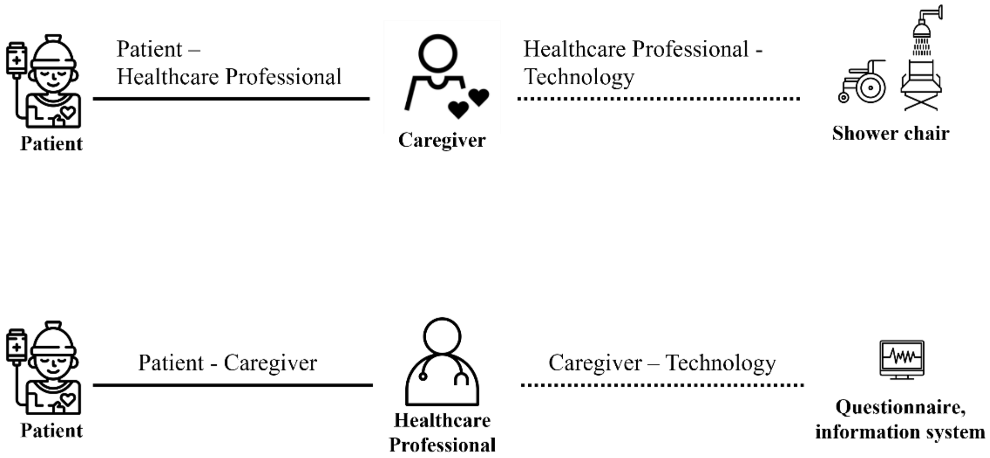


Figure 15. Actors and associations

Patient (prioritized voice), healthcare professional (“voice of medicine” [Vasconcellos-Silva et al., 2007]), and family caregiver (prioritized voice when the patient’s voice cannot be prioritized) qualified as actors. Each promoted a difference in the other or the network. Patient and healthcare professional had one association, patient and caregiver had another, connected by continuous lines in Figure 15. There was no permanent direct association between healthcare professionals and caregivers.

Technology as a tool was interpreted as an intermediary; it only passed between these two actors and defined their relationship (Callon, 1990). Technology assisted the service encounter; the physician used exams, electronic health records, information system, and health assessment questionnaires, and the caregiver deployed the daily task (e.g., showering the patient) (Froehle and Roth’s, 2004). Patient and technology did not have an actor-intermediary association.

The three actors formed one association at the consultation, illustrated in Figure 16. They interacted, shared information, explained treatment-related topics, asked questions, corrected deviations, and gave orders on these occasions. It resembled what Callon (1984) called an ‘obligatory passage points’ in the network of building relationships.

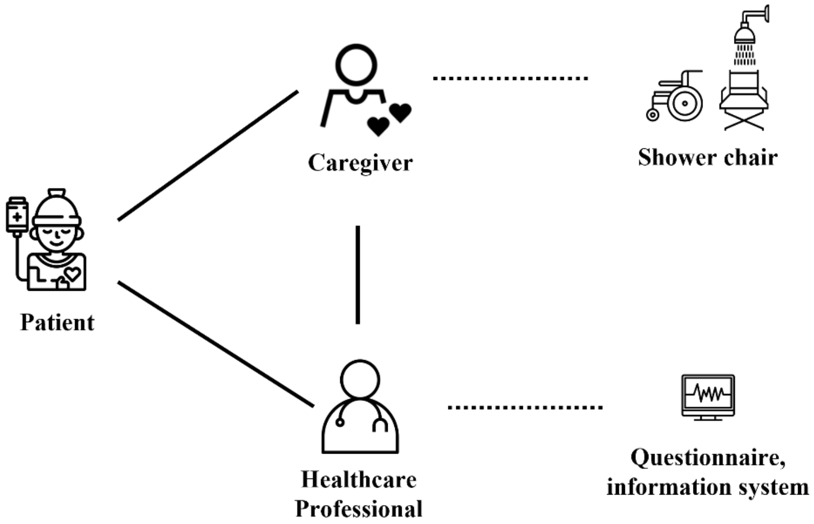


Figure 16. Actors and associations during the consultation

The family caregiver was observed as an actor throughout the answers. However, it is not always the exercised agency. In the consultation, the family caregiver's exercise of agency is "granted" by the patient's condition and ability to communicate, or the physician's information needs. Particularly when granted by the physician, agency is tied to the scope of the caregiving role and its (expected) tasks and actions. This will be explored later.

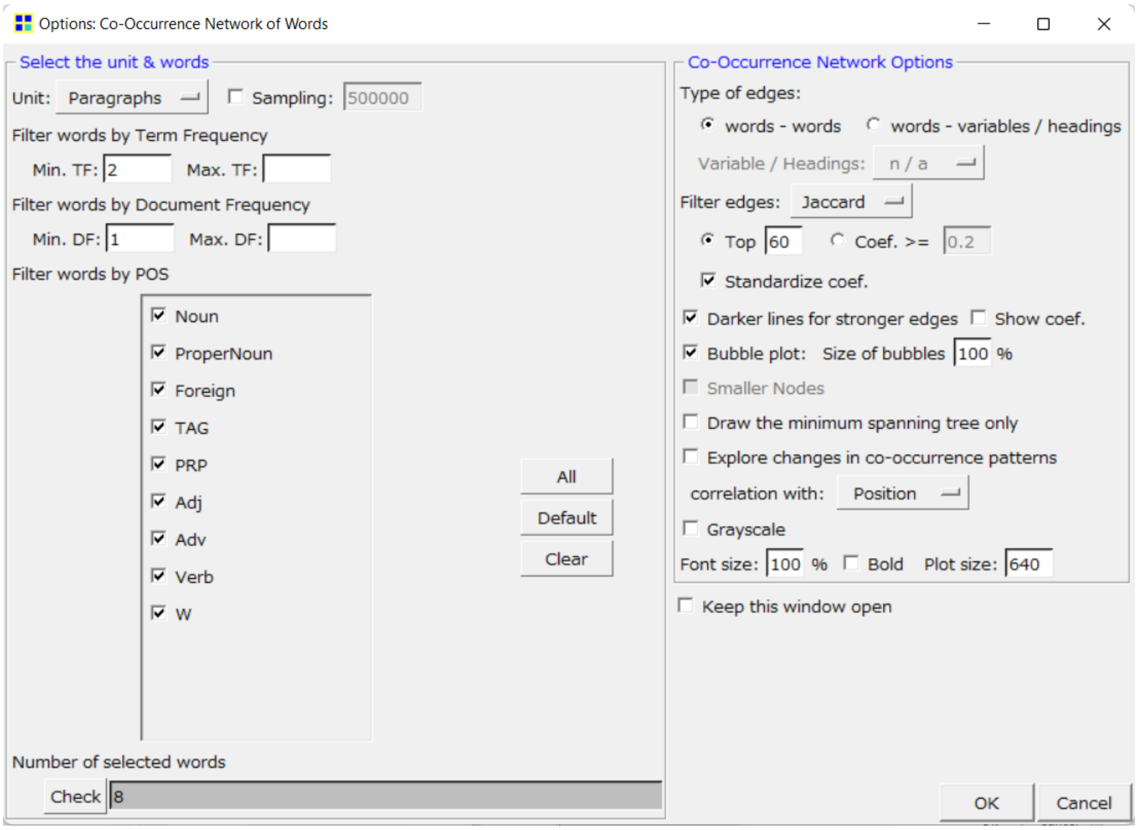
Once agency was granted, the caregiver assumed the post of primary information source. In most cases, the information concerned the treatment, planning and decision-making, deployment, monitoring, or tasks and action (e.g., *"When I applied pre-diabetic injections, as per medical advice," "Observation of symptoms," "When the patient is too ill or unsure," "Choice of whether or not an intervention can be carried out, a burdensome decision imposed on the caregiver to protect medical professionals from being sued")*.

4.3.3. Analysis 3: contrasting co-occurrence networks of words

The text analysis was performed using KH Coder version 3.Beta.02f [Perl 5.14.2, Perl/Tk 804.03], free software distributed under the GNU General Public License developed by Professor Higuchi Koichi from Ritsumeikan Daigaku. It is widely used in research in various fields: 4892 published papers utilized the software to date. KH Coder was chosen to support the text-mining exercise because of its easy-to-use interface, clear manual instructions, reliability, and available functions, such as the Co-Occurrence Network of Words.

The Co-Occurrence Network of Words generates a network of words closely related to a specific term. Words closely associated with one another are connected by lines (Higuchi, 2016, pp. 42, 43). These words have similar appearance patterns, meaning they have high degrees of co-occurrence, and it has been successfully used since the beginnings of content analysis (Higuchi, 2016, p. 50). This function was implemented to visualize the groups of topics and their combinations in the answers from the family caregivers and physicians.

A text file (.txt) was created for the answers to questions 2, 3, 4, 5, and 6[4]. Family caregivers had one text file; physicians had another. As a result, there were ten text files. Each file was uploaded to the software, pre-processed, and had its co-occurrence networks diagrams generated. The same filtering criteria were used to generate them, shown in Figure 14.



Select the unit & words

Unit: Paragraphs ☐ Sampling: 500000

Filter words by Term Frequency

Min. TF: 2 Max. TF:

Filter words by Document Frequency

Min. DF: 1 Max. DF:

Filter words by POS

☑ Noun
☑ ProperNoun
☑ Foreign
☑ TAG
☑ PRP
☑ Adj
☑ Adv
☑ Verb
☑ W

Number of selected words

Check 8

Co-Occurrence Network Options

Type of edges:

● words - words ○ words - variables / headings

Variable / Headings: n / a

Filter edges: Jaccard

● Top 60 ○ Coef. >= 0.2

☑ Standardize coef.

☑ Darker lines for stronger edges ☐ Show coef.

☑ Bubble plot: Size of bubbles 100 %

☐ Smaller Nodes

☐ Draw the minimum spanning tree only

☐ Explore changes in co-occurrence patterns

correlation with: Position

☐ Grayscale

Font size: 100 % ☐ Bold Plot size: 640

☐ Keep this window open

Figure 17. Co-occurrence network of words diagrams: filtering criteria

The filtering criteria followed the default options suggested by the software. Edges (co-occurrences) were filtered with Jaccard coef., the default option in the software. This meant that only edges equal or greater than a specified threshold appeared in the diagrams (Higuchi,

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[4] (Caregivers) 2. Please share with us situations you feel the voice of patient is prioritized. 3. Please share with us situations you feel the voice of caregiver is prioritized.; 4. How do you think the healthcare professional involves the patient in the treatment (role in treatment) and what actions do you think he usually expects from patient?; 5. How do you think the healthcare professional involves the caregiver in the treatment (role in treatment) and what actions do you think he usually expects from caregiver?; 6. Now, think of the treatment in its entirety (first and subsequence consultations). How do you see the information and knowledge shared by patient and caregiver throughout treatment to be utilized by healthcare professional in practical terms?
(Healthcare Professionals) 2. Please share with us situations when the voice of patient is prioritized.; 3. Please share with us situations when the voice of caregiver is prioritized.; 4. How do you involve the patient in the treatment (role in treatment) and what actions do you usually expect from him/her during treatment?; 5. How do you involve the caregiver in the treatment and what actions (role in treatment) do you usually expect from him/her during treatment?; 6. Now, think of the treatment in its entirety (first and subsequence consultations). How do you utilize the information and knowledge shared by patient and caregiver throughout treatment in practical terms?

2016, p.51); a node (word) that did not meet the criteria would not be shown. Minimum term frequency set at 2. Additionally, “Darker lines for stronger edges” was checked to highlight words that have stronger occurrences according to the coefficient value for the diagram. Next, the diagrams were displayed and analyzed.

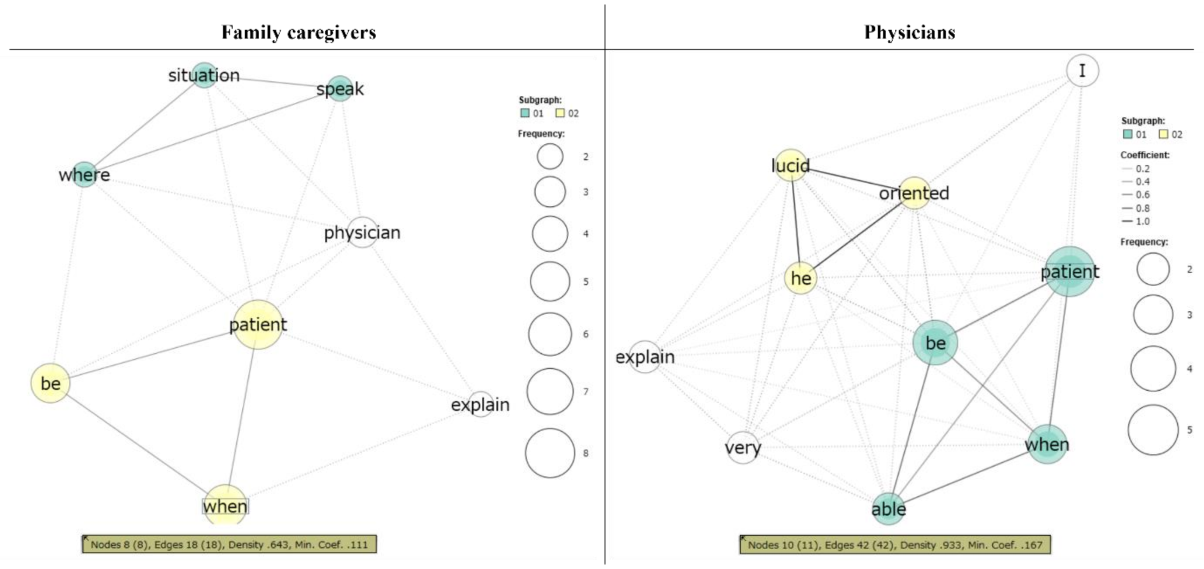

Figure 18. Question 2: Situations when the patient’s voice was prioritized

The patient voice was prioritized when explaining their physical state (e.g., symptoms, discomforts), illustrated in Figure 18, conditioned by their ability to communicate how they felt. This further confirms the previous analysis.

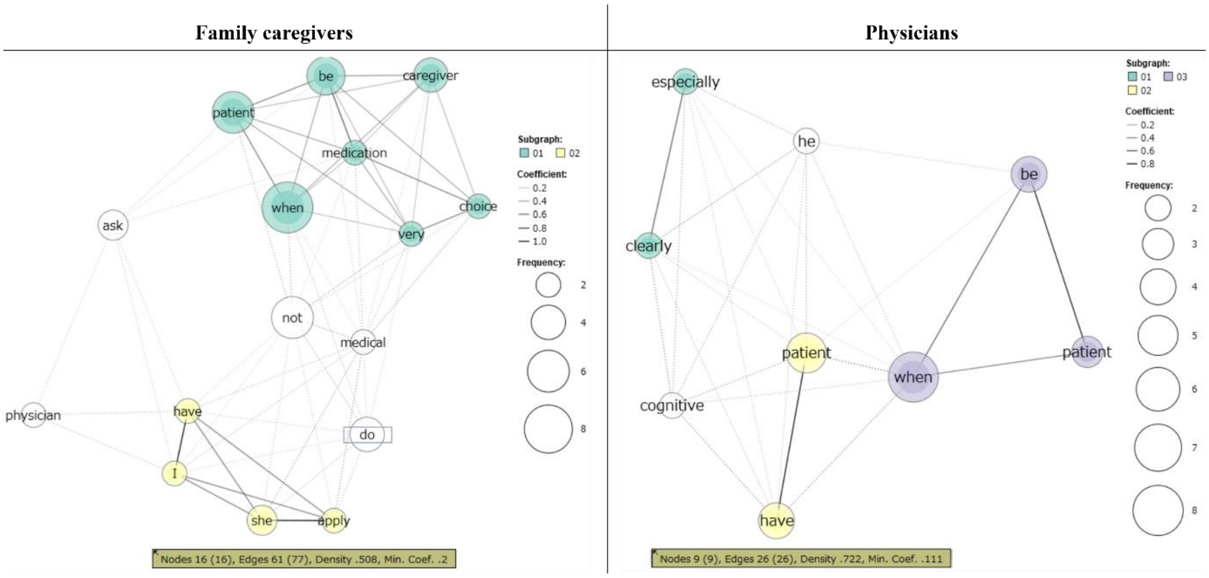

Figure 19. Question 3: situations when the caregiver’s voice is prioritized

The patient’s ability to communicate their wishes or how they felt determined whether the caregiver's voice was prioritized, as per Figure 22, expressed by physicians through "occasionally, in long-term, care when the patient is no longer able to communicate his wishes", "when there is any impossibility to receive patient information", or when the patient has some degree of dementia , I prioritize the caregiver 's voice".

Family caregivers reported the physician's request for information about patient follow-up, observation of symptoms and use of medication (e.g., "when asking about medications the patient is taking", "observation of symptoms when patient cannot identify or distinguish symptomatic behavior or reaction"). So, whenever complementary information about the treatment was needed (i.e., deployment, daily operations, and results), the professionals resorted to the caregiver.

The family caregiver role shaping is conditioned by voice prioritization. Although part of a dyad, the caregiver remained in the background and occupied a central position only when the patient could not. There are two complementary types of information sought by the physician: physical state-related information collected from the patient and treatment-related, collected from the caregiver only when needed.

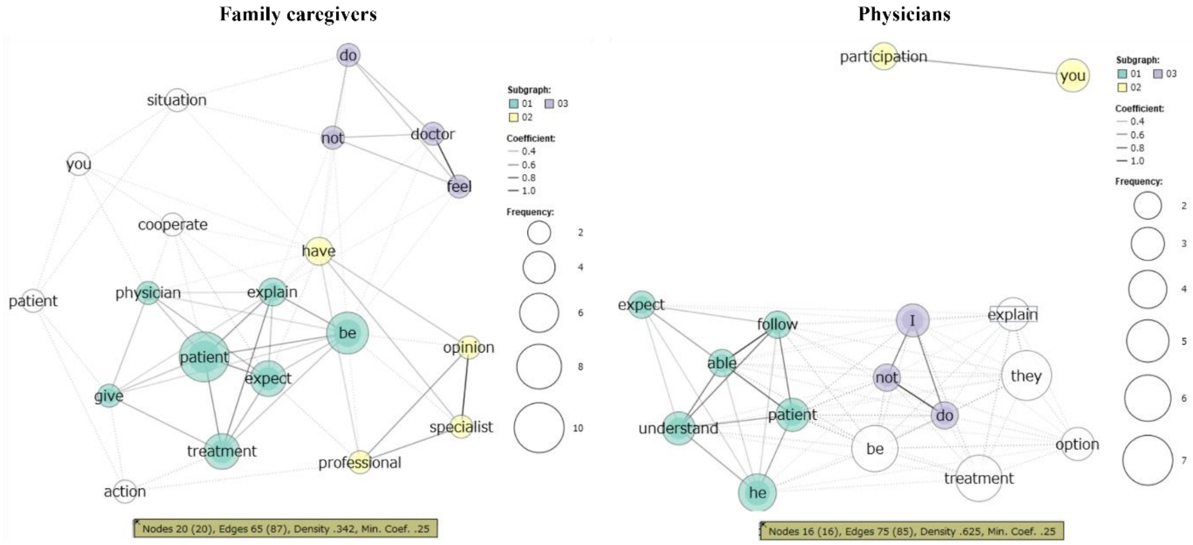

Figure 20. Question 4: how the patient is involved in the treatment and their expected actions

The physicians involved the patients when they explained the situation, the treatment and its importance, treatment options if any with pros and cons, and when they motivated the patient about life (e.g., "I explain and expect adherence to treatment"; "the patient is involved when he is able to understand guidelines and prescriptions"; "motivating the patient about life"). The patient is expected to understand the explanation, cooperate, and correctly follow instructions to accomplish the success of the treatment, displayed in Figure 20. But, according to one caregiver, "very few doctors and nurses explain clearly the procedure of the treatment as it is being carried out if patient is conscious, patient is not asked how s/he is feeling at each stage".

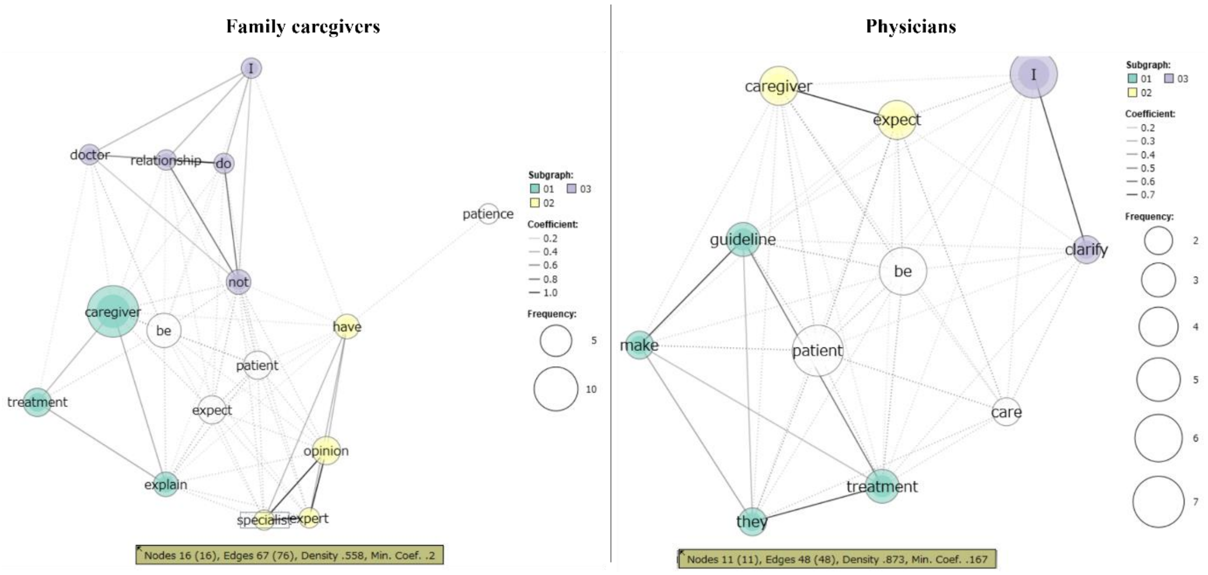

Figure 21. Question 5: how the family caregiver is involved in the treatment and expected actions from them

Physicians involved family caregivers when they were asked to accompany the patients to the consultations and enquired about the treatment (e.g., “I ask the caregiver to accompany the encounter, I expect help”). They explained the treatment guidelines to the patient and the family caregiver (e.g., "the patient 's inability to understand makes the caregiver's involvement necessary, it is expected that this will help the patient in following the guidelines and prescriptions"), shown in Figure 21.

It was expected that caregivers supervised and helped in the treatment and ensured that instructions were correctly followed, though these actions are expected not to intervene excessively. The caregiver was expected to be a collaborator in the background whose interventions cannot be excessive (e.g., "how to help the treatment work"; "check caregiver from excessive intervention in the two-way relationship between the caregiver and the patient, expect actions that do not intervene excessively").

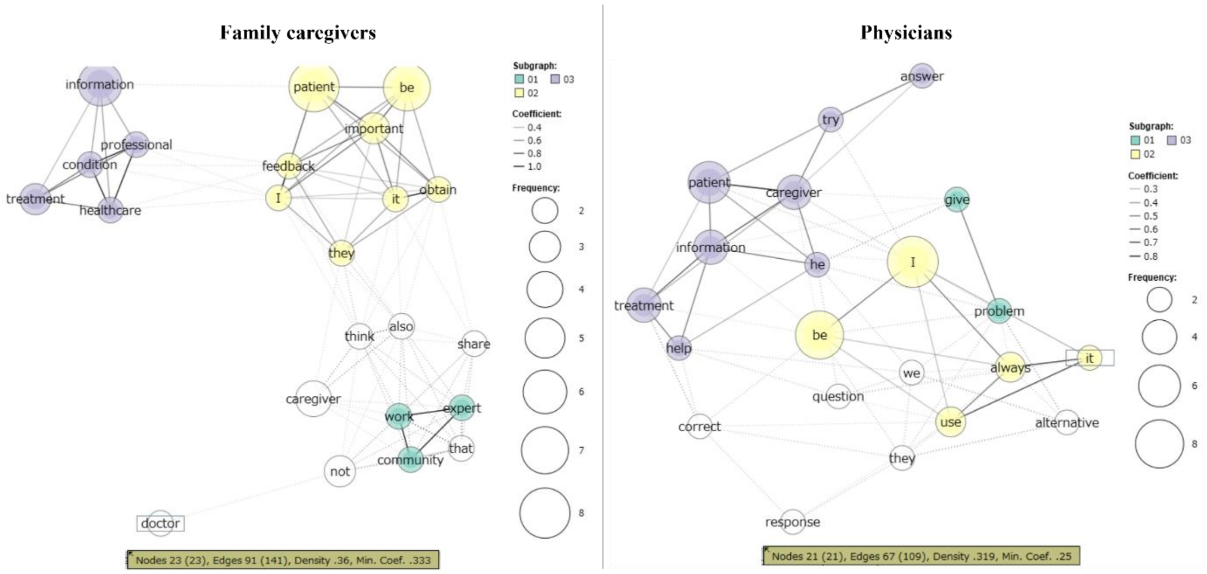

Figure 22. Question 6: utilization of information and knowledge shared by the patient and the caregiver during the treatment

Caregivers and physicians acknowledged that the caregivers' and patients' information was applied to correct treatment deviations and make pragmatic decisions, displayed in Figure 22. Physicians reported this information was essential to the treatment. As treatment progress was assessed, patients and caregivers were included in finding alternatives, ways to improve it, and making decisions about the treatment. Although the patient’s feedback was prioritized, one physician believed that “the feedback given by the caregiver is often more relevant, since they are in a neutral situation in relation to the health problem.”

The caregivers reported it was “important to share lived situations and results obtained with certain attitudes.” In this testimony, the accomplishment resulted in learning and adapting the shower chair to the patient’s height. It was reported that physicians lacked interest in the details. For these family caregivers, their information and details ensured a highly targeted and effective treatment because they can depict the dyad's context daily.

4.3.4. Analysis 4: understanding the tasks and actions

Analysis 4 utilized the answers to questions 2, 3, 4, 5, and 6[5] to clarify the inner dynamics of the associations and understand the shaping of the caregiver role based on tasks and actions (the division of labor).

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[5] (Caregivers) 2. Please share with us situations you feel the voice of patient is prioritized. 3. Please share with us situations you feel the voice of caregiver is prioritized.; 4. How do you think the healthcare professional involves the patient in the treatment (role in treatment) and what actions do you think he usually expects from patient?; 5. How do you think the healthcare professional involves the caregiver in the treatment (role in treatment) and what actions do you think he usually expects from caregiver?; 6. Now, think of the treatment in its entirety (first and

The caregiver, physician, patient, and family caregiver worked together to achieve the objectives of getting things done and establishing the patient's well-being. These objectives gave meaning to this association (Engeström, 2008, p. 204). At times, the medical consultation had aspects of “knotworking” where collaboration is vital (Engeström, 2008, p. 208).

Knotworking happens when knots are temporarily formed, then dissolved, and re-formed over time without a fixed endpoint (Engeström, 2008, p. 196); it is an answer to a continuous need to co-configure the object of activity with all its involved parties. Knots are a formation of otherwise loosely connected actors who quickly come together for a task and work out a collaborative performance (Engeström, 2005). When knotworking, “no single actor has the sole, fixed authority—the center does not hold” (Engeström, 2006).

After accomplishing the consultation’s goal, the physician, the patient, and the family caregiver parted ways and that knot dissolved until the next consultation, illustrated in Figure 23. However, based on the respondents’ answers, the authority was fixed on the physician—the leader and voice of medicine—and the center held mostly on the patient—the prioritized voice.

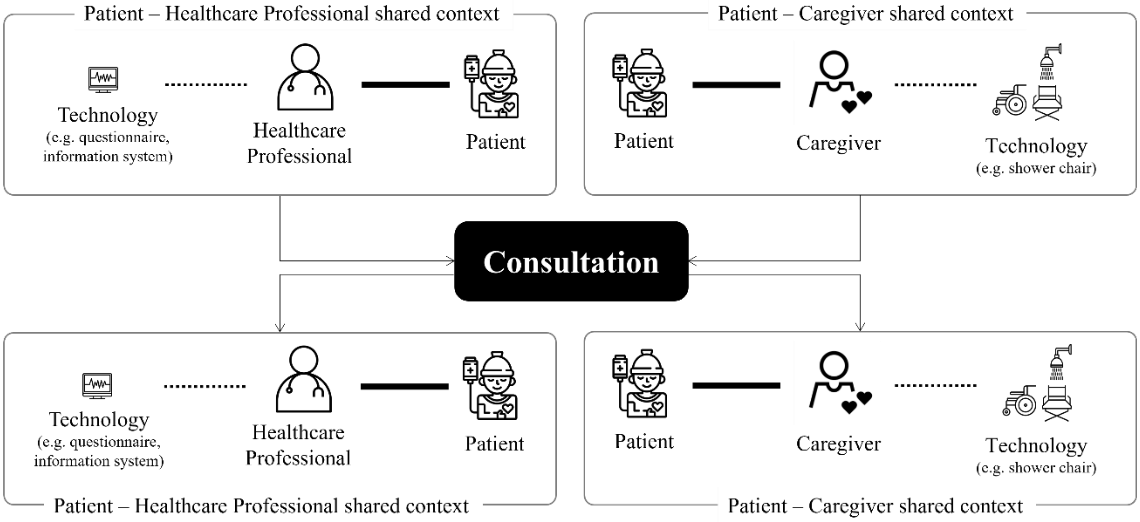

Figure 23. The consultation in the treatment

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subsequence consultations). How do you see the information and knowledge shared by patient and caregiver throughout treatment to be utilized by healthcare professional in practical terms?
(Healthcare Professionals) 2. Please share with us situations when the voice of patient is prioritized.; 3. Please share with us situations when the voice of caregiver is prioritized.; 4. How do you involve the patient in the treatment (role in treatment) and what actions do you usually expect from him/her during treatment?; 5. How do you involve the caregiver in the treatment and what actions (role in treatment) do you usually expect from him/her during treatment?; 6. Now, think of the treatment in its entirety (first and subsequence consultations). How do you utilize the information and knowledge shared by patient and caregiver throughout treatment in practical terms?

The consultation allowed the patient, physician, and caregiver to come together and share one context. It was the event where interactions took place; physicians could assess the patient's well-being, advise on following steps, support decision-making processes, teach the caregiver about treatment deployment, and assign tasks; the encounter is illustrated in Figure 23. The tasks and actions (the division of labor) are consolidated in Table 13.

Table 13. Tasks and actions the treatment's actors

Actor	Tasks and actions	Tasks and actions (Expected by caregiver)	Tasks and actions (Expected by physician)
Physician	Leads treatment ("voice of medicine") Listens to patient Assesses patients based on their feedback (sometimes, caregiver's) feedback Explains the framework of care, treatment options, and its guidelines Explains the need for treatment Assigns tasks, prescribes medication, and sets next treatment steps based on assessment and information provided by the patient (sometimes, by caregiver) Motivates patient about life Consults caregiver when the patient is unable to communicate Teaches caregivers about medication and how to apply it Collects consent from the patient	Listen to patient and caregiver Allow caregiver to share contextual details about patient, treatment and listen to it carefully Teach medication and application method Offer clear explanation about treatment guidelines and procedures Give instructions (lead)	
Patient	Connects physician and caregiver Makes decisions about treatment Provides information for health assessment, treatment deviations detection, and correction		Understand of treatment's importance Decide on the treatment option Adhere to treatment Follow instructions and cooperate for treatment success Motivation
Caregiver	Deploys the day-to-day treatment Applies medication Provides information about the operational side of treatment Accompanies patient to consultations Supports patient and treatment adherence		Accompany patient to consultations. Communicate patient's physical state when s/he is unable to. Inform about treatment daily operations. Supervision, aid, attention, and support to patient and treatment

Makes decisions about treatment	Compliance with treatment guidelines Medication application No excessive intervention

The (expected) tasks and actions identified boundaries around the family caregiver, patient, and physician roles in this sample. Next, the results of the analyses are discussed to answer the research question and list the study's theoretical and practical implications.

4.2. Discussion

There are primarily two approaches to the process of role enactment in research. Structuralists view roles as fixed positions in the social structure occupied by individuals who internalize the expected behavior that comes with the role taken (Ebaugh, 1988, p. 18). Symbolic interactionists tend to see them as fluid and constantly negotiated shared understandings (Ashforth, 2000, p. 4), making (Ebaugh, 1988, p. 19), or shaping a role instead of taking it. In the former, the role is stiff; one complies with expectations, and there is not much room for transformations. In the latter, a dynamic continued negotiation seems to be the only path to avoid role obsolescence.

This study's main finding concerns the different family caregiver role shaping processes based on the analyses. The caregiver performed to an audience, an actor in the association of physician-patient-caregiver, the audience influenced how the role was shaped. There were fixed tasks and actions when the audience was the healthcare professional (i.e., physician).

The information or knowledge shared was about these fixed and expected tasks and actions. The role performance was assigned based on reported information about the care recipient's condition for treatment planning, orders giving and tasks assignment.

In this interaction, the family caregiver role had a pre-defined shape; there were fixed tasks and actions, and they were expected to behave accordingly. There was little room for reflection or negotiation. The shared information or knowledge was limited to these fixed tasks and expected actions.

When the interaction was with the care recipient, the daily caregiving demands and the dyadic structure of the care recipient-family caregiver relationship imposed constant transformation of tasks and actions. This way, the family caregiver could continue providing suitable care to the care recipient. This care was based on the circumstance at hand. The list of tasks and actions was often revised, renewed and the role shaping looked like a continuous process. In this case, role performance was dynamic, rooted in tasks and close action with and towards the care recipient to handle the situation. It was hands-on assistance.

Excerpts from physicians and family caregivers presented in Table 14 illustrate the difference in role shaping process based on to whom the role was being performed.

Table 14. Excerpts from physician's, family caregivers' answers and the shaping of this role.

Physicians	**Family caregivers**
"When there is any impossibility to receive patient information."	*"When I applied some pre-diabetic injections, according to medical guidelines, as she did not want to apply it to her, as she did not have the courage."*
"Use of medications. Dose, dosage."	*"Physician asks the caregiver for an answer."*
"When the patient has communication difficulties."	*"Physician explains the treatment to caregiver so that caregiver is able to care for patient at home."*
"Trace the patient's profile and therapeutic response."	*"Physician checks caregivers from excessive intervention in the two-way relationship between the caregiver and the patient. Expect actions that do not intervene excessively."*
"The information given by the patient is prioritized. On the other hand, I believe that the feedback given by the caregiver is often more relevant, since he is in a neutral situation in relation to the health problem."	*"I expect that the healthcare professional would try to analyse and understand from the information given, so that he can better treat the patient, based on the patient's condition and feedback arising from the treatment. This is important as every patient is different after all."*
"(...) information by the patient and his caregiver helps us make more pragmatic decisions that would facilitate the treatment process of the patient."	*"It is important to share lived situations. Results obtained with certain attitudes. For example, adaptations made to the bath chair when the patient is short."*
"I try to gather patient and caregiver information to get as close to reality as possible, allowing me to define the best treatment for the case."	*"How to help the treatment work."*
"When asking about medications the patient is taking."	*"Doctor checks if the treatment is being carried out. Obey the caregiver."*
"I'm showing them the positive or negative results, and together looking for alternatives and ways to improve. Explaining the alternatives, we have to always solve the problem."	*"Voice of caregiver prioritised: When asking about medications the patient is taking."*

When interacting with the healthcare professional, the caregiver role shaping was conditioned by the care recipient and the condition. Outside this interaction, when it happened with the care recipient, the caregiving role is shaped with the person cared for through actions, hands-on-everyday assistance. The caregiver is called from backstage when the care recipient cannot provide the necessary information about their physical state. The patient's information was sufficient to set the treatment guidelines in most cases. The caregiver was a supportive character and an overall treatment information provider, willing to share their contextual knowledge for an effective and targeted treatment.

When interacting with the care recipient, the caregiver was the care deployer sharing center stage with the care recipient. They were practitioners with deep understanding and knowledge of the care recipient and their caregiving needs, active knowledge creators who used customized tools for comfort and successful task accomplishment. The result of these lived experiences was a tacit knowledge and an understanding shared by the caregiver and the care recipient.

Although this thesis concerns the performance of the family caregiver in this role, the shaping of it can be understood from the role-identity perspective, as proposed by the caregiver identity theory which posits that the caregiver experiences distress or burden because of a disruption in their own identity maintenance process. It explains that family caregiver goes through a dynamic identity change process while performing caregiving tasks and actions and as care requirements evolve. As this occurs, the relationship is between the now caregiver and care recipient in transformed from a primarily familial one into a caregiving relationship (Montgomery and Kosloski, 2013, p. 137).

This process of identity change is propelled by the changes in the caregiving context, required performance, and derives directly from the constantly evolving interaction between caregiver and care recipient. The individual who is providing care either stretches (or assimilates) caregiving tasks into the existing role-identity or accommodates the new tasks undermining the current role-identity. This generates a discrepancy; the individual must change the role-identity or reject the caregiver role (Montgomery and Kosloski, 2013, pp. 137-138).

The caregiver identity theory draws from the interactionalist school of role shaping to explain caregivers’ trajectories and how they resolve discrepancies from this role. For this theory, role shaping is dynamic and a result of the interplay between caregiving context and the evolving relationship that caregiver and care recipient have. The findings in our study are aligned with what the theory posits and adds that there is a static side of the family caregiver role shaping that happens when they interact with the physician; it is based on tasks and actions ordering/assignment.

In summary, when guided by the structural approach, the caregiver role has a pre-defined shape based on expected behavior patterns dictated by social norms, and deviation is not expected. The role is dynamic and negotiated with the audience when guided by the interactionalist approach; it is constantly shaped and transformed to avoid obsolescence.

Additionally, a gap was found between the perceived quality of the information provided by the family caregiver to healthcare professionals and the caregiver's perception that these professionals lacked "interest in the details" contained in this information. The caregiver knows and shares (or wants to share) details about the care recipient and the treatment, which did not seem to interest the professional. The healthcare professional acknowledged the accuracy of this information.

Lundvall and Johnson (1994) proposed four types of knowledge: *know-what* refers to facts and resembles what is typically called information; *know-why* refers to scientific knowledge; *know-how* refers to skills acquired through practice; *know-who* is about knowing people (e.g., who knows what or how to get something done) (Foray and Lundvall, 1998, pp. 115-116). In nursing practice, *know-that* and *know-when* were added to the list. *Know-that* refers to the choice of action determined by situation, skills, and patient's preference—it is about knowing a particular intervention is required; *know-when* closely relates to *know-that* because it refers to the moment in time when an action/required intervention is appropriate (Oberle and Allen, 2001).

Know-that and *know-when* are highly contextual, involve the care recipient, and a lot of knowledge about them is gained through close contact and interaction that feeds their *know-who*. From the data, family caregivers possess these types of knowledge in abundance and derive a lot from their *know-how* gained through performing in the caregiver role.

From the analysis, the healthcare professionals were the voice of the medicine and the expected treatment leaders. They possessed strong *know-what*, *know-why*, *know-how*; they *knew who* the care recipient was from the medical consultations and knew other professionals for referrals if necessary. Based on this knowledge, they *knew when* to intervene and *knew that* a certain intervention was required.

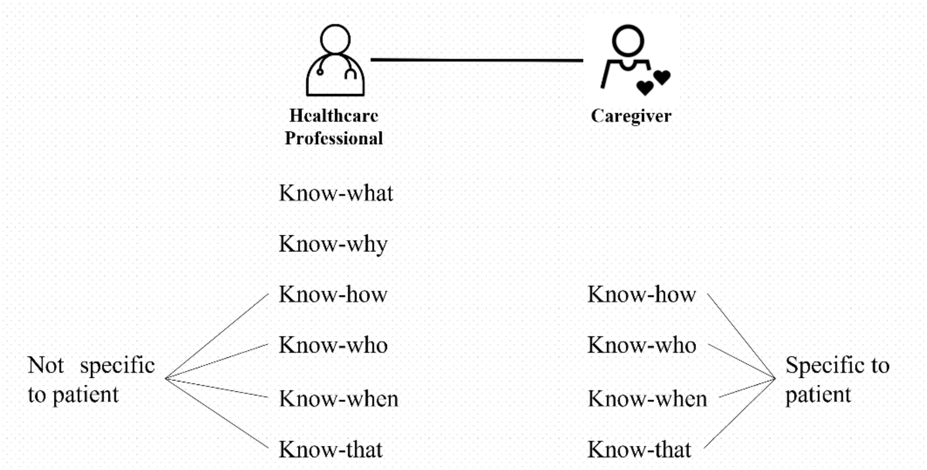


Figure 24. Sources of contextual practice-based knowledge

Based on this, it is argued that the differences in the caregiver's *know-when* and *know-that* derived from the *know-how* based on situations that involved the care recipient. Conversely, the *know-when* and *know-that* the healthcare professional possessed derived from the know-what, know-why, know-how, and know-who of various experiences throughout their career and had a more general and factual character, illustrated in Figure 24.

Furthermore, the healthcare professional is the expert performer in that task environment with a vast stock of concrete experiences that built their expertise (Dreyfus, 1982). This constructed know-how to recognize a pattern of symptoms in a situation and intuitively decide how to treat the care recipient (Honken, 2013). This intuition is possible "because each typical whole salienced situation, unconsciously synthesized from several experienced concrete situations, now has associated with it a specific response or type of response which experience has shown to be appropriate." (Dreyfus, 1982).

What appeared as a lack of interest in the details might have been the search for specific information allowing the healthcare professional to recognize a pattern and look for a specific response based on previous successful experiences.

The practical implications of this study are directed at healthcare professionals. During the medical consultation, reserve some time to interact specifically with the caregiver. Make it a routine to allow them an opportunity to provide the highly contextual knowledge they are willing to share. Involve them by turning them into contextual knowledge providers and not just overall treatment information providers. It may be helpful to use a standard questionnaire with questions on the scope of their caregiving role to clarify what it encompasses for effective support.

Based on The Dreyfus Model of Skill Acquisition, Patricia Benner (1982) developed a model of skill acquisition specific for the nursing practice. It comprises five levels of proficiency: novice, advanced beginner, competent, proficient, and expert. As the practitioner advances through these levels, two aspects of skilled performance change. One aspect is a movement from relying on abstract principles to relying on past, concrete experiences. The other is a change in the perception of a circumstance, from a collection of bits where all are pertinent to a whole situation whose only certain parts are pertinent (Benner, 1982) for understanding that situation and acting on it.

This model assesses nurses' skills and appropriately trains them to improve their proficiencies. Future research can propose such a similar model specific to family caregivers. It can be a useful tool in providing support to the caregiver by understanding their proficiency level and designing effective training that will cater to their specific knowledge need, targeting their expert level accomplishment. It may improve the interactions because the level of proficiency can be known, and the caregiver can perform their role accordingly.

This study's due to limited financial and time resources, which the authors acknowledge as limitations. However, slight, it was possible to understand how the caregiver role is shaped. It might have been useful to conduct in-depth interviews with some respondents to understand the gap of perceptions found; however, contact information was not collected for follow-up interviews. Perhaps this limitation can be addressed in a future study.

4.3. Conclusions

This chapter’s goal was to understand how the shaping of the caregiver role occurred through the interaction between the caregiver and healthcare professional. The data for analyses were collected through an online survey and answered by eight healthcare professionals and 12 family caregivers. Hermeneutic analysis and interpretation uncovered respondents’ practices. The framework method was applied to sort humans and non-humans and clarify their associations and expected tasks and actions (the division of labor). Text analysis was conducted to generate a co-occurrence network of words to contrast answers.

The findings suggested that when the interaction was with the healthcare professional, the caregiver role had a pre-defined shape and a stiff structure of tasks and actions, based on expected behavior patterns where deviation was not expected. When interacting with the care recipient, the shape of the role was dynamic and negotiated, often being shaped; tasks and actions were transformed to avoid role obsolescence. As a result, it was concluded that family caregivers are holders of highly contextual practice-based knowledge that can significantly contribute to building a targeted and effective treatment tailored to the care recipient.

This study showed through the different processes of role shaping that the source of contextual practice-based knowledge that healthcare professionals possess differs from the family caregivers. Family caregivers possess the latest knowledge about the care recipient due to the close relationship and care delivery. They can significantly contribute to designing a targeted treatment tailor-made to the care recipient.

This is probably the first study that contrasted tasks and actions (expected to be) carried out by the healthcare professionals and the caregivers and how interactions between them influenced the shaping of the family caregiver role.

The next chapter presents the final remarks.

Chapter 5 - Conclusions

Motivated by the contribution family caregivers provide to the care recipient, other family members, and the healthcare system, this study aimed to understand the family caregiver role, its scope of tasks and actions, how it is shaped and the toll on the lives of those who perform the service. Discover ways in which family caregivers' caregiving experience can be improved while performing in the caregiver role and being effectively used by patient-centred and home care approaches to ensure treatment success.

The focus of this thesis was the family caregiver, conceptualized as practitioners and members of the healthcare team who deploy care at the last mile (i.e., the home). They unite with the care recipient (i.e., patient) and form a dyad in the care. Caregiving is demanding, and it profoundly affects the life of the caregiver.

The purpose of this thesis was to understand the family caregiver's experience from a role performance angle and provide suggestions to help improve their caregiving experience. This was achieved through understanding the impact of a family caregiver's sense of role loss on the caregiving experience where the unit of analysis was the caregiver (Study 1 in Chapter 3). This research examined the shaping of family caregiver role through interactions with healthcare professionals based on tasks and actions with the caregiver and the healthcare professional as the unit of analysis (Study 2 in Chapter 4). Each study covered one part of the internal and external fields of caregiving.

The family caregiver role is multi-faceted and constantly evolving as the care recipient's condition progresses. Well-supported family caregivers see positive impacts on their psychological and physical health. The support may come from other family members, healthcare professionals, associations, and so on. Throughout this research, the authors participated in many online seminars for family caregivers and, as many said during those sessions, "it takes a village to provide care."

The studies presented in this thesis addressed two research questions:

RQ1: How does a family caregiver's sense of role loss impact the caregiving experience?

RQ2: How is the family caregiver role shaped through interactions between the family caregiver and the healthcare professional?

Developed in Chapter 3, Study 1’s Research Question 1 aimed at understanding how a family caregiver’s sense of role loss impacted their caregiving experiences. The data for analysis were collected through an online survey and answered by 66 individuals. The framework method was employed to organize the data into themes for analysis.

The findings shed light on and indicated the possibility of generating the sense of caregiver role loss when these individuals rotate through held roles. Role rotation allows family caregivers to step out of caregiving from time to time. The sense of caregiver role loss can be a tool to maintain or regain a sense of personal choice in life and self-priority.

As presented in Chapter 4, Study 2’s Research Question 2 explored understanding how the caregiver role's shaping occurred through the interaction between the family caregiver and healthcare professional. The data for analyses were collected through an online survey and answered by eight healthcare professionals and 12 family caregivers. Hermeneutic analysis and interpretation uncovered respondents’ practices. The framework method was applied to sort humans and non-humans and clarify associations and expected tasks and actions. Text-mining was conducted to generate a co-occurrence network of words to contrast answers.

The findings suggested that when the interaction was with the healthcare professional, the family caregiver role had a pre-defined shape; there were fixed tasks, and the family caregiver was expected to behave according to expectations. There was little room for reflection or negotiation. The shared information or knowledge was limited to these fixed tasks and expected actions.

When the interaction was with the care recipient, the daily demands of the caregiving activity and the dyadic structure of the care recipient-family caregiver relationship imposed constant negotiation and transformation of tasks and actions so that the role continued to be relevant. With this, the family caregiver could continue providing the most suitable and customized care to the recipient. This care was based on the circumstance at hand. The list of tasks and actions was often revised and renewed, and role shaping is continuous.

A strong support system can help family caregivers practice role rotation more often. Informational and emotional support increased their preparedness to deal with the circumstances at hand. Family caregivers are holders of highly contextual practice-based knowledge about care recipients. They can help develop effective treatments with a patient-centered approach. Based on the findings and literature reviewed, the current (sort of) “knot” arrangement can improve to incorporate this knowledge more effectively in triadic care.

Based on this research’s goal and the results from Studies 1 and 2 in Chapters 3 and 4, the overall practical and theoretical implications are laid out next.

5.1 Theoretical implications

The necessity to rely on so many theories (Role Exit Theory, Role Transitions Theory, Cultural-Historical Activity Theory, Nonaka and Konno’s ba, Actor-Network Theory) to try and understand the caregiver role and caregiving experience proves just how complex the activity is.

For instance, Role Exit and Role Transitions Theories allowed a better understanding of the impact of caregiving on the roles through which a family caregiver occupies and rotates. They also guided the analysis to understand their sense of role loss and its impact on the caregiving experience.

Cultural-Historical Activity Theory was employed to break down the caregiving activity and understand how the caregiver role is shaped based on tasks, actions, and expectations. The division of labor sheds light on the inner dynamics of the healthcare professional, care recipient, and family caregiver’s associations by breaking tasks and actions down to the individual level. Additionally, tools are highlighted here because they are used to accomplish an activity’s goals.

The association of the healthcare professional, care recipient, and family caregivers resembled knotworking. In this mode of working and learning, actors collaborate, and no one holds the authority: “the center does not hold” (Engeström, 2006). From these samples, the authority seemed to rely on the healthcare professional; the center usually held on the care recipient of health professionals.

Nonaka and Konno’s ba focuses on human interactions and practice-derived highly contextual knowledge and does not consider technology a potential actor. Conversely, Actor-Network Theory sees humans and non-humans (e.g., technology) as actors if any promotes difference in others or the network; technology is used extensively during treatment.

In medical consultation, technology was a tool to get things done. However, a tool can be challenging as the caregiver must find a way to customize it to best fit the care recipient’s current needs. When this is achieved, it gains the status of a tool to accomplish a task. This was the case of one respondent who devised a way to adapt the height of a shower chair.

This theoretical research contribution is consolidated in Table 15.

Table 15. Theoretical implications from this research

Theory	Use in this thesis to	Implication
Sense of role loss, Roles, Role Exit, Role Transitions Theories	Understand role occupation, exit, and entry	Role rotation and generation of a sense of caregiver role loss
Cultural-Historical Activity Theory (CHAT) and knotworking	Understand the inner dynamics of activity based on the division of labor and expectations/rules	Knotworking is not seen much in triadic care because the triad itself is still to be in full form; the family caregiver’s highly contextual practice-based knowledge is not fully utilized yet
Caregiver Identity Theory and dynamic/interactionalist caregiver role-identity shaping process	Understand family caregiver role shaping from a performance and role-identity perspective	There is also a more static aspect of family caregiver role shaping based on tasks and actions ordering and assignment by healthcare professional that needs to be explored to understand its impact on the caregiving experiences

There is a need to develop a framework that can help understand the caregiving activity and streamline the combination of different knowledge during treatment. Furthermore, this framework should help us analyze and understand the ways in which a dyad plus one is transformed into a true triad during the caregiving period. This will consider the caregiver role construction through both static/reporting and dynamic/taking action. It must encompass characteristics of the theories used in this study and, at the same time, try to fill the identified gaps. In the subsequent paragraphs, an attempt to lay out the grounding rules of this framework are presented. It is up to future research to improve and pursue them.

Role performance requires a performer and an audience. In this research, the act of performing in a role is permeated by interaction between the one who performs and the ones who watch and perform their own role. Caregivers gave us a glimpse of their routine, face-to-face conversations, interactions, and actions while performing in the role; they make their thoughts, feelings, and intentions – their subjectivity - synthesized. With other communicating selves (i.e. care recipient, healthcare professionals), this synthesis is merged and emerged into intersubjectivity (Wiley, 1988).

A starting point of this framework would require that the caregiver is conceptualized as a member of the caring team who performs the caregiving activity at the last mile. It is the caregiver that the care team entrusts the task of care deployment daily and of keeping the team up to date about the care recipient.

This conceptualization aims at tearing certain communication walls down to allow interactions among the team members to happen more easily. It is expected to streamline the emergence of intersubjectivity between communicating selves and allow for negotiations, exchanges and knowledge creating sessions through understanding and development of role scopes. Sense of belonging is expected to rise from both sides: caregivers more certain they are well supported by their team and the healthcare professionals will have a chance to look at the caregivers as team members.

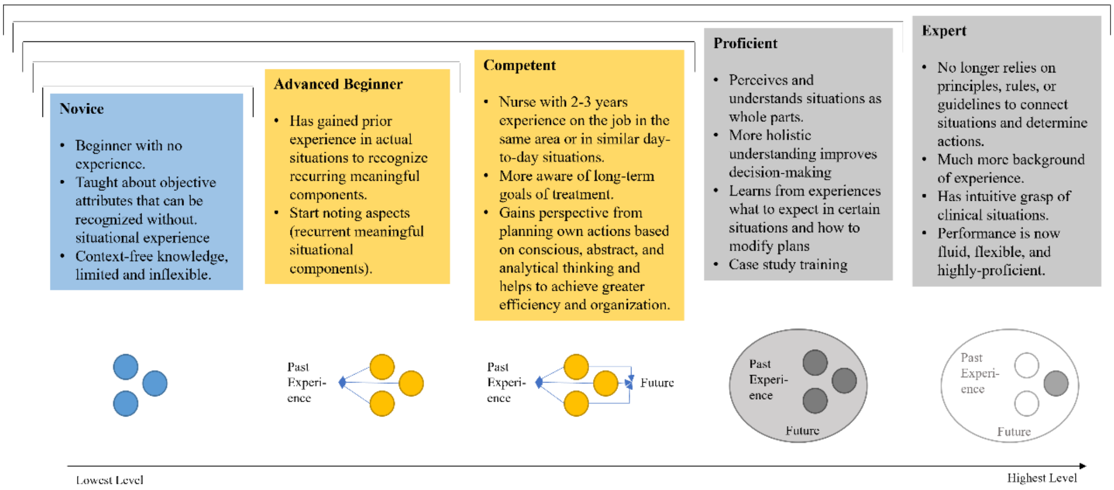
Role scopes and intersubjectivity will allow to draw a robust skeleton of the components of the caregiving experience. The framework should look at caregiving as a myriad of components that make up the entire experience. These elements are not a fixed list, future studies can continue to add and refine this list. The different combination (or existence) of these elements and their interplay makes up for the uniqueness of each of caregiving experience. By analyzing this composition, it is possible to understand the dynamics of a particular caregiving activity and provide targeted support based on that. A first version of this framework could be achieved through a literature review of existing studies.

Next, the framework must install a continuous practice of “deference to expertise” which allows decisions to migrate to the person or team who has the specific knowledge of the event (Weick & Sutcliffe, p. 115). For instance, healthcare professionals attentively listen to the caregiver’s description of a caregiving episode; the professional proposes alternatives and decisions are made: each participant defers to the expertise of the other that is/was necessary to resolve an issue.

To ensure good quality decision making through deference to expertise, develop a model of skill acquisition specific to the family caregiver, which will best fit their journey. This model will aid the development of specific tools that will help healthcare professionals support caregivers, promoting a more dynamic caregiver role construction. It will also assist in training caregivers based on their skill level.

As explored in Chapter 4, Benner (1982) developed a model of skill acquisition specific for the nursing practice based on The Dreyfus Model of Skill Acquisition

(Dreyfus, 1982). It comprises five proficiency levels, including novice, advanced beginner, competent, proficient, and expert, illustrated in Figure 25.



Novice

- Beginner with no experience.
- Taught about objective attributes that can be recognized without. situational experience
- Context-free knowledge, limited and inflexible.

Advanced Beginner

- Has gained prior experience in actual situations to recognize recurring meaningful components.
- Start noting aspects (recurrent meaningful situational components).

Competent

- Nurse with 2-3 years experience on the job in the same area or in similar day-to-day situations.
- More aware of long-term goals of treatment.
- Gains perspective from planning own actions based on conscious, abstract, and analytical thinking and helps to achieve greater efficiency and organization.

Proficient

- Perceives and understands situations as whole parts.
- More holistic understanding improves decision-making
- Learns from experiences what to expect in certain situations and how to modify plans
- Case study training

Expert

- No longer relies on principles, rules, or guidelines to connect situations and determine actions.
- Much more background of experience.
- Has intuitive grasp of clinical situations.
- Performance is now fluid, flexible, and highly-proficient.

Figure 25. Benner's Model of Acquisition Skills in nursing practice

As practitioners advance through these levels, two aspects of skilled performance change. One aspect is a movement from relying on abstract principles to depending on past, concrete experiences. The other is a change in the perception of a circumstance as less of a collection of bits where all are pertinent to a whole situation whose only certain parts are pertinent (Benner, 1982) for understanding that situation and acting on it.

This model is used to assess a nurse’s skills and appropriately train them to improve their proficiency levels. Future research can propose a similar model specific to family caregivers that best suits their skills acquisition journey and caregiving experience. This can be accomplished through in-depth interviews with family caregivers, associations and other service provider who support caregivers.

5.2 Practical implications

Supporting family caregivers was a key aspect for enhanced role performance. This support may come from family and friends (emotional support), healthcare professionals (informational and emotional support), or governments (financial and informational support).

The informational and emotional support provided by healthcare professionals helped family caregivers deal better with the circumstances at hand. It helped them better understand the care recipient and the caregiver role, look at caregiving as a constantly changing process, and devise mechanisms to deal with their reported sense of role loss. It was clear that knowledge and learning are crucial for the caregiver’s effective performance and empowerment, control over situations, and mechanisms to deal with caregiving's emotional, physical, and social tolls.

Practical implications concern the re-conceptualization of the family caregiver as a true healthcare team member. First, the team must identify the family caregiver in charge of the care in the internal field. Then, recognize and acknowledge the family caregiver as a team member to integrate them in all treatment steps and effectively use their knowledge. Furthermore, with a family caregiver model of skill acquisition, the team will assess the caregiver’s skill level and design and provide training to fit their information and knowledge needs.

Healthcare professionals need to be trained to properly assess the family caregiver’s scope of tasks and skills level and support them accordingly. Such training and accurate assessment will also help them calibrate their language to ensure the illness stage and treatment plan are clearly understood by both the caregiver and care recipient. The objective is to propel the caregivers to achieve expertise.

Healthcare professionals may invite the family caregiver's active participation in treatment, and it may be helpful to know them on a more personal level. This can be done by establishing a collaborative environment through conversations and learning about the role's tasks. Acknowledging the caregiver’s contribution by sharing their highly contextual practice-based knowledge and work will contribute to their well-being and performance.

5.3 Limitations

Many family caregivers continue to work, and the caregiving role is an additional responsibility. This group is expected to grow in the following years with changes in demographics. This thesis did not explore the interaction of the family caregiver with the enterprise where they work. There is a lot to uncover about this interaction and how these enterprises can effectively support individuals who need to work while advancing in their careers while caring for others.

There is strong evidence for the claims in Study 1 (Chapter 3). The claims in Study 2 (Chapter 4) are based on a combination of theory and findings from a small sample size, and more evidence is needed to advance this understanding. Future research can elaborate an empirical study based on Study 2’s findings to clearly identify where family caregivers can be used effectively in the treatment.

Lastly, the first of the five goals listed in the latest Recognize, Assist, Include, Support, and Engage (RAISE) report to guide policies that will improve family caregivers' lives (LeaMond, 2021) recommends increasing awareness about family caregivers and their various needs and challenges. The author hopes to have contributed to raising awareness through this thesis.

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Appendix 1. The online questionnaire (sense of role loss)

Caregiver and Sense of Role Loss

Hello! My name is Lisa Ribeiro. I am a second year PhD student at the Tokyo Institute of Technology (Tokyo, Japan) and investigator in this study. With my Academic Advisor, Prof. Senoo, our research focuses on family members who become family caregivers.

When change pushes individuals (e.g., currently in family member role) into new roles (e.g. caregiver role), they reportedly have a sense of role loss – which is usually felt when one senses a change in role or responsibility, relationship distancing or changed asymmetry. The sense of role loss can be defined as the feeling one has when his known pattern of behaviour and skills no longer apply to a new performance expectation enacted by change in a situation or context. It can be disorienting and freeze one's ability to enter the new role and, eventually, develop a sense of role gain.

This survey will take about 10 to 25 minutes of your time. We deeply appreciate your collaboration.

In this study, a caregiver is a relative, partner, friend or neighbour who has a significant personal relationship with and provides a broad range of unpaid assistance for another person with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the care recipient.

*Required

Informed Consent

You are asked to complete this survey to help us in our research about the sense of role loss felt by caregivers. The objective is to find family caregivers for an interview and ask for permission to collect their contact information. You are completely anonymous in this process. No names or any other identifying information will be used when discussing or reporting data.

You may withdraw from your participation at any time without penalty.

By consenting to this form, you authorize the use and disclosure of the following information for this research: observations and findings found during the course of this study for education, publication and/or presentation.

Investigator's e-mail: ribeiro.l.ac@m.titech.ac.jp

0. Do you voluntarily agree to participate in this survey? *

( ) Yes
( ) No (Participation declined.)

Section 1

1. Your gender: *

( ) Male
( ) Female

( ) Another Gender Identity
( ) Not Specified

2. How long have you been a caregiver? *

( ) Less than 1 year 1 to 2 years
( ) 2 to 3 years
( ) 3 to 4 years
( ) 4 to 5 years
( ) More than 5 years
( ) I am no longer a caregiver

3. Do you and the person cared for share the same home? *

( ) Yes
( ) No

4. Relationship with the person cared for: *

( ) My husband / male partner
( ) My wife / female partner
( ) My father
( ) My mother
( ) My son
( ) My daughter
( ) My brother
( ) My sister
( ) My uncle
( ) My aunt
( ) My father-in-law
( ) My mother-in-law
( ) My friend
( ) Other:

5. Do you share the care giving tasks with anyone else? *

( ) Yes
( ) No

Section 2: BEFORE caregiving activity start

About roles: throughout life, we perform many roles: worker, student, family member, caregiver. Role participation is associated with physical, cognitive, and psychosocial skills necessary to perform it. We frequently go through role transitions: we exit and enter roles constantly. They can be macro (for example, operator promoted to supervisor job) or micro (for example, one moment I am a subordinate to a director and, the next, I am my team's leader). Role loss and role gain happen often.

6. Before you became a caregiver, what FIRST (main) role did you perform more frequently? *

( ) Student (I.e. attending school on a part-time or full-time basis)

( ) Worker (I.e. part-time or full-time paid employment)
( ) Volunteer (I.e. donating services, at least once a week, to a hospital, school, community, political campaign, and so forth)
( ) Caregiver (I.e. responsibility, at least once a week, for the care of someone such as a child, spouse, relative, or friend)
( ) Home maintainer (I.e. responsibility, at least once a week, for the upkeep of the home such as housecleaning or yard work)
( ) Friend (I.e. spending time or doing something, at least once a week, with a friend)
( ) Family member (I.e. spending time or doing something, at least once a week, with a family member such as a child, spouse, or other relative)
( ) Religious Participant (I.e. involvement, at least once a week, in groups or activities affiliated with one's religion)
( ) Hobbyist / Amateur (I.e. involvement, at least once a week, in a hobby or amateur activity such as sewing, playing a musical instrument, woodworking, sports, the theatre, or participating in a club or team)
( ) Participant in organisations (I.e. involvement, at least once a week, in organisations such as civic organisations, political organisations, and so forth)
( ) Other

6.1. How would you rate your performance in the role above (question 6)? *

Poor 1 2 3 4 5 Excellent

7. Before you became a caregiver, what SECOND role did you perform more frequently? *

( ) Student
( ) Worker
( ) Volunteer
( ) Caregiver
( ) Home maintainer
( ) Friend
( ) Family member
( ) Religious Participant
( ) Hobbyist / Amateur
( ) Participant in organisations
( ) Other

7.1. How would you rate your performance in the role above (question 7)? *

Poor 1 2 3 4 5 Excellent

8. Before you became a caregiver, what THIRD role did you perform more frequently? *

( ) Student
( ) Worker
( ) Volunteer
( ) Caregiver
( ) Home maintainer
( ) Friend
( ) Family member

( ) Religious Participant
( ) Hobbyist / Amateur
( ) Participant in organisations
( ) Other

8.1. How would you rate your performance in the role above (question 8)? *

Poor 1 2 3 4 5 Excellent

Section 3: AFTER caregiving activity start

9. After becoming a caregiver, what FIRST (main) role do you perform more frequently? *

( ) Student
( ) Worker
( ) Volunteer
( ) Caregiver
( ) Home maintainer
( ) Friend
( ) Family member
( ) Religious Participant
( ) Hobbyist / Amateur
( ) Participant in organisations
( ) Other

9.1. How do you rate your performance in the role above (question 9)? *

Poor 1 2 3 4 5 Excellent

10. After becoming a caregiver, what SECOND role do you perform more frequently? *

( ) Student
( ) Worker
( ) Volunteer
( ) Caregiver
( ) Home maintainer
( ) Friend
( ) Family member
( ) Religious Participant
( ) Hobbyist / Amateur
( ) Participant in organisations
( ) Other

10.1. How do you rate your performance in the role above (question 10)? *

Poor 1 2 3 4 5 Excellent

11. After becoming a caregiver, what THIRD role do you perform more frequently? *

( ) Student
( ) Worker

( ) Volunteer
( ) Caregiver
( ) Home maintainer
( ) Friend
( ) Family member
( ) Religious Participant
( ) Hobbyist / Amateur
( ) Participant in organisations
( ) Other

11.1. How do you rate your performance in the role (question 11)? *

Poor 1 2 3 4 5 Excellent

Section 4: You, the caregiver

In this section, we try to learn a little more about you and your care giving activity.

12. What event led you to become a caregiver? (1 to 3 lines) *

13. Please describe how you felt when you became a caregiver. (1 to 3 lines) *

14. To you, what does it mean to be a caregiver? (1 to 3 lines) *

15. As a caregiver, I... *

☐ Assist with care recipient's personal care
☐ Prepare or buy food
☐ Perform general health care tasks
☐ Assist with care recipient's mobility
☐ Supervise care recipient and his/her care
☐ Take care of transportation of the care recipient
☐ Give emotional support to care recipient
☐ Arrange back-up care (or respite) services
☐ Organise the home
☐ Monitor my and care recipient's health
☐ Customise or troubleshoot equipment used by the care recipient
☐ Advocate for care recipient access to appropriate general and medical services
☐ Participate in associations and attend courses for caregivers
☐ Ensure my and the care recipient's well being
☐ Other:

16. Through an image or a metaphor, describe how being a caregiver is. (1 to 5 lines). Examples: "Caregiving is having/being in a story." (Golden et al., 2012). "It is like planning and making all the necessary preparations of a of family trip. And, after boarding the plane, we are suddenly re-routed to another city." (Thomson, 2020) *

17. Have you have settled in the role of caregiver? *

( ) Yes
( ) No
( ) Still trying to
( ) Not sure if I have Not anymore

( ) Other

18. If you can, please describe this process of settling in the role of caregiver. (1 to 5 lines)

19. Your country *

20. In case we need more information, may we contact you? If so, please inform your name, e-mail (or phone number) below.

Thank you for answering this survey!

Or

Participation declined. You have elected not to participate in this research. You can click on "Submit" button or simply close your browser. Thank you!

Appendix 2. R script for text analysis (text after “#” are comments).

```
# Read the text file from local machine, choose file interactively
text <- readLines(file.choose()) # .txt file with answers from Groups 35, 27 and 4.

# Load the data as a corpus
TextDoc <- VCorpus(VectorSource(text))

#Replacing "/", "@" and "|" with space
toSpace <- content_transformer(function (x , pattern ) gsub(pattern, " ", x))
TextDoc <- tm_map(TextDoc, toSpace, "/")
TextDoc <- tm_map(TextDoc, toSpace, "@")
TextDoc <- tm_map(TextDoc, toSpace, "\\|")

# Convert the text to lower case
TextDoc <- tm_map(TextDoc, content_transformer(tolower))

# Remove numbers
TextDoc <- tm_map(TextDoc, removeNumbers)

# Remove english common stopwords
TextDoc <- tm_map(TextDoc, removeWords, stopwords("english"))

# Remove own stop word
TextDoc <- tm_map(TextDoc, removeWords, c("mother", "care", "caregiver",
"caring", "father", "son", "daughter", "husband", "wife", "sister", "brother",
"duchene", "alzheimers", "alzheimer's", "alzheimer", "autism", "disease", "recipient"))

# Remove punctuations
TextDoc <- tm_map(TextDoc, removePunctuation)

# Eliminate extra white spaces
TextDoc <- tm_map(TextDoc, stripWhitespace)

# Text stemming - which reduces words to their root form
TextDoc <- tm_map(TextDoc, stemDocument)

# Build a term-document matrix
TextDoc_dtm <- TermDocumentMatrix(TextDoc)
dtm_m <- as.matrix(TextDoc_dtm)

# Sort by descearing value of frequency
dtm_v <- sort(rowSums(dtm_m),decreasing=TRUE)
dtm_d <- data.frame(word = names(dtm_v),freq=dtm_v)

# Display the top 10 most frequent words
head(dtm_d, 10)

# Find associations (top 10 most frequent words (root))
findAssocs(TextDoc_dtm, terms = c("life","love", "take"), corlimit = 0.50)
```

Appendix 2. Table of themes (all)

ERA Framework	**Experience**			**Reflection**		**Action**
Reflective Cycle	**Description: What happened?**	**Feelings: What were the caregiver's feelings and thoughts?**	**Evaluation: What was good and bad? How was the experience perceived?**	**Analysis: What sense did the caregiver make of the situation?**	**Conclusion: Settling in and wrap-up thoughts about the experience**	**Action plan: How was settling in the role? What/How did the caregiver do/adapt?**
Online Survey Question	**12. Event that led into caregiving** **3. Shares home** **5. Shares tasks**	**13. Feelings upon becoming a caregiver**	**16. Metaphor or image of caregiving**	**14. What it means to be a caregiver**	**16. Describe the process of settling in the caregiver role (feelings, experience)**	**16. Describe the process of settling in the caregiver role (actions to settle in)**
Group 35	12. Event Illness (20) Injury (7) Death of in-charge of care (4) Disability (4)	TH051 - Worry and anxiety due to a sense of unpreparedness for providing for care recipient's needs, feeling of loss. (11)	TH063 - Focus on the present situation, accepting one does not know what will come in near future, a situation can change quickly. (13)	TH070 - Work for and provide for needs of care recipient anytime. (17)	TH083 - Continuous learning, settling in the caregiver role as a long process. (4)	TH090 - Continuous learning to adapt to changing demands of caregiving while trying to balance personal life. (9)
	3. Shares Home Yes (29) No (6)	TH052 - Lack of time and freedom to pursue personal and professional lives (no choice). (7) TH053 - Strong will to help and be useful to others, hopeful. (7)	TH059 - Life taking a turn that the caregiver did not deliberately choose. (4) TH065 - Very low priority put on personal life activities, difficulty to plan activities with others. (4)	TH069 - Give up personal choice in life, give up personal life. (6) TH071 - Be available and present, always-on mode. (6) TH073 - Give love and support to the care recipient. (6)	TH079 - Sudden new reality to attend to. (3) TH080 - Give up personal life, change to personal life. (3) TH081 - Difficulty in settling in the role, no recipe for the role. (3)	TH091 - Support and learning from professionals and associations helped adapt to the role or to be able to pursue personal life activities. (4)

		TH064 - Constant availability, be present. (4) TH066 - Love, support, patience. (4)			
5. Shares Tasks No (21) Yes (14)	TH055 - Responsibility, duty. (5)	TH062 - Dedication and work for the care recipient’s well-being. (3) TH067 - Responsibility, duty. (3)	TH075 - Be many-in-one, wear many hats as a caregiver. (2)	TH082 - Initially easy, increasingly more difficult and demanding. (2) TH087 - Care recipient is the priority, dedication. (2)	TH089 - Focus on the current situation and attend to it as it requires. (2) TH092 - Responsibility, duty. (2) TH093 - Care became a routine. (2)
	TH056 - Determination to get things done, adaptation to it. (4) *TH054 - Physical, emotional, or financial exhaustion. (3)* *TH057 - Solitude, abandonment. (2)* *TH057 - Following values passed down by previous generations. (1)* *TH050 – A relief to have a diagnosis. (1)* *TH058 -Difficulty in accepting reality. (1)*	*TH060 - Ability to flourish in the caregiver role. (1)* *TH061 - Self-knowledge, knowing what one can and cannot do. (1)* *TH068 - Gratefulness for care recipient’s condition improvements. (1)*	*TH072 - Find meaning in the caregiver role for both caregiver and care recipient. (1)* *TH074 - Transmit values. (1)* *TH076 - Slavery. (1)* *TH077 - Responsibility. (1)*	*TH078 - Realization that the situation would not change and need to find peace and joy in life. (1)* *TH084 - Routine. (1)* *TH085 - Normal. (1)* *TH086 - Exhaustion. (2)*	*TH088 - Locate purpose and meaning in little things. (1)*

Group 27	12. Event Illness (15) Death of in-charge of care (7) Disability (2) Injury (2) Help (1)	TH003 - Worry and anxiety due to a sense of unpreparedness for providing for the care recipient's needs. (12)	TH017 - Be present to support and understand the care recipient. (7)	TH024 - Work for and provide for the needs of the care recipient anytime. (17)	TH035 - Difficulty in settling in the caregiver role. (4)	TH044 - Understanding of the care recipient and their condition. (4)
	3. Shares Home Yes (23) No (4)	TH002 - Sense of pride to be helpful. (4)	TH019 - Alertness to constantly monitor and adapt to the situation at hand. (5)	TH027 - Act of love. (6)	TH031 - Continuous learning for constant adaptation to the role. (3) TH032 - Sudden new reality to attend to. (3)	TH042 - Determination to face and overcome challenges. (3) TH046 - Immediate and instinctive settling in the caregiver role and its demands. (3) TH043 - Learn with and receive support from professionals, associations, attending training. (3)
	5. Shares Tasks Yes (16) No (11)	TH004 - Responsibility, duty. (3) TH006 - Physical or emotional tiredness. (3) TH008 - Demanding activity with a positive side. (3)	TH015 - Lack of time and freedom to pursue personal things. (4)	TH025 - Selflessness. (2)	TH034 - Exhaustion. (2) TH036 - Decisions that led to loneliness and low priority put on the personal side of life. (2)	TH041 - Realization that caregiving requires continuous learning. (2)
		TH001 - Willingness to support. (1)	*TH014 - Act of love. (3)*	*TH022 - Prepare one's future. (1)*	*TH033 - Self-Sacrifice. (1)*	*TH045 - Redefinition of*

		TH005 - Sense of changed relationship. (1) *TH007 - Sense of preparedness (attended training). (1)* *TH009 - Sadness. (1)* *TH010 - Happiness. (1)*	*TH011 - Give and receive (now or in future). (2)* *TH016 - Change in role. (2)* *TH020 - A challenge. (2)* *TH012 - Demanding mission. (1)* *TH013 - To be more and better. (1)* *TH018 - Destiny. (1)* *TH021 - Intimate and profound experience. (1)*	*TH023 - Give and receive (now or in future). (1)* *TH026 - Gratitude. (1)* *TH028 - Responsibility. (1)* *TH029 - Pride. (1)* *TH030 - Faith. (1)*	*TH037 - Interesting. (1)* *TH038 - Responsibility, duty. (1)* *TH039 - Emotional value. (1)* *TH040 - “Ain’t no mountain high enough”. (1)*	*caregiver’s life priorities. (1)* *TH047 - Love, duty. (1)*
Group 4	12. Event Injury (2) Disability (1) Illness (1)	TH101 - Worry and anxiety due to a sense of unpreparedness for providing to care recipient’s needs. (2) TH102 - Lost, alone, lack of support. (2) TH103 - Courage, gratitude, strength from love. (2)	TH105 - Lack of support, process inefficiencies, paperwork. (2) TH108 - Unexpected turn of events, a sudden new reality to attend to. (2)	TH109 - Work for and provide for the needs of the care recipient anytime, an act of help. (2)	TH114 - In the past, easier. Now, more difficult, less energy than when started. (2)	TH117 - Maintenance of/participation in activities/events outside the caregiver role. (1) TH118 - Learn with and receive support from professionals, associations, attend training. (1) TH119 - Left job to focus on care. (1) TH120 - Received support from a housekeeper. (1)
	3. Shares Home Yes (4)	TH100 - Caregiving as a natural/anticipated path. (1)	TH104 - Give up personal life to prioritize caregiving,	TH110 - Availability. (1)	TH115 - Difficulty in seeing others ‘having a life’	

	being an extension of the care recipient, stop living own life to dedicate to care. (1) TH106 - Resources demanding activity (especially, financially). (1) TH107 - Love. (1)	TH111 - Act of love. (1) TH112 - Comforting. (1) TH113 - Exhaustion. (1)	when the caregiver is not. (1) TH116 - Had to do what was necessary to support the care recipient/s. (1)
5. Shares Tasks Yes (1) No (3)			

Appendix 3. Caregiver’s online questionnaire (shaping of the caregiver role).

Patient and caregiver roles during treatment (Caregiver)

Hello! Thank you for helping me with our research. My name is Lisa, currently on my 1st year of PhD course at the Tokyo Institute of Technology.

This research is about knowledge creation throughout treatment among healthcare professional, patient and caregiver (i.e. family member, partner, professional caregiver). Our aim is to understand the dynamics of knowledge sharing and creation among these three actors and its application in treatment to increase "technical and functional quality of healthcare services and patient well-being" (Zhao et al., 2015).

Reference: Zhao, J., Wang, T. and Fan, X. (2015). Patient value co-creation in online health communities: Social identity effects on customer knowledge contributions and membership continuance intentions in online health communities. *Journal of Service Management, Vol. 26 No. 1,* pp. 72-96. https://doi.org/10.1108/JOSM-12-2013-0344

* Required

Scenario: Think of when you accompany a patient (i.e. family member, partner) as a caregiver to a consultation. Please try to recall how such consultations usually go and answer freely the following questions.

1. For majority of the cases, whose voice do you feel is prioritized by the healthcare professional? *
( ) Voice of the patient
( ) Voice of the caregiver

2. Please share with us situations you feel the *voice of patient* is prioritized. *

3. Please share with us situations you feel the *voice of caregiver* is prioritized. *

4. How do you think the healthcare professional involves the *patient* in the treatment (role in treatment) and what actions do you think he usually expects from patient? *

5. How do you think the healthcare professional involves the *caregiver* in the treatment (role in treatment) and what actions do you think he usually expects from caregiver? *

6. Now, think of the treatment in its entirety (first and subsequence consultations). How do you see the information and knowledge shared by patient and caregiver throughout treatment to be utilized by healthcare professional in practical terms? *

7. Country *

Thank you for kindly answering the questionnaire!

Appendix 4. Healthcare professional’s online questionnaire (shaping of the caregiver role).

Patient and caregiver roles during treatment (Healthcare professional)

Hello! Thank you for helping me with our research. My name is Lisa, currently on my 1st year of PhD course at the Tokyo Institute of Technology.

This research is about knowledge creation throughout treatment among healthcare professional, patient and caregiver (i.e. family member, partner, professional caregiver). Our aim is to understand the dynamics of knowledge sharing and creation among these three actors and its application in treatment to increase "technical and functional quality of healthcare services and patient well-being" (Zhao et al., 2015).

Reference: Zhao, J., Wang, T. and Fan, X. (2015). Patient value co-creation in online health communities: Social identity effects on customer knowledge contributions and membership continuance intentions in online health communities. *Journal of Service Management, Vol. 26 No. 1*, pp. 72-96. https://doi.org/10.1108/JOSM-12-2013-0344

* Required

Scenario: Think of when a patient comes for a consultation and the caregiver accompanies him/her. Please try to recall how such consultations usually go and answer freely the following questions.

1. For majority of the cases, do you prioritize the voice of the patient or the voice of the caregiver? *
( ) Voice of the patient
( ) Voice of the caregiver

2. Please share with us situations when the *voice of patient* is prioritized. *

3. Please share with us situations when the *voice of caregiver* is prioritized. *

4. How do you involve the *patient* in the treatment (role in treatment) and what actions do you usually expect from him/her during treatment? *

5. How do you involve the *caregiver* in the treatment and what actions (role in treatment) do you usually expect from him/her during treatment? *

6. Now, think of the treatment in its entirety (first and subsequence consultations). How do you utilize the information and knowledge shared by patient and caregiver throughout treatment in practical terms? *

7. Country *

8. Profession *

Thank you for kindly answering the questionnaire!

List of Publications

Original papers

1. Ribeiro, L., Ho, B. Q., & Senoo, D. (2021, October). How Does a Family Caregiver's Sense of Role Loss Impact the Caregiving Experience?. In *Healthcare* (Vol. 9, No. 10, p. 1337). Multidisciplinary Digital Publishing Institute. Corresponds to Chapter 3.

2. Ribeiro, L., & Senoo, D. (2020, April). An Autopoietic View of the Ba and Its Adaptation: the Dynamics of Acquaintanceship, Knowledge Gaps, and Importance of the Concept in Knowledge Creation. *Kindai management review, 8,* 63-80. Corresponds to Chapter 4.

Proceedings

3. Ribeiro, L., & Senoo, D. (2021, July). Understanding How Patient, Caregiver and Healthcare Professional Come Together During Treatment. In *International Conference on Knowledge Management in Organizations* (pp. 125-137). Springer, Cham. Corresponds to Chapter 4.