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## Research Article

# “It Is about How Kind They Are”: The Significance of Professionals’ Attitudes towards Caregivers in the Dutch Care System

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In recent years, Dutch authorities have attempted to shift from formal to informal care responsibilities to meet an increasing demand for care. There is a growing expectation that social and healthcare professionals will actively involve, support, and collaborate with partners, family members, and others who provide informal care. However, the practical implementation of such collaborations is not yet evident. In this qualitative study, 37 individual interviews and eight focus groups were conducted to explore the preferences of informal caregivers in the Netherlands regarding their collaboration with social and healthcare professionals. In recognition of the growing consensus that professionals should tailor their approach to caregivers’ individual circumstances, we adopted an intersectional approach to examine the relationship between caregivers’ social positions and preferences as well as the impact of systemic and power dynamics on these collaborations. The findings indicate that most of caregivers’ worries concerning collaborations are rooted in the organisational context of their interactions with professionals rather than the interactions themselves. Caregivers’ social positions do not necessarily lead to varying opinions regarding collaboration with professionals; however, caregivers do expect professionals to be aware of their social positions, as these positions shape the context within which informal care is provided and determine how easily caregivers can integrate care responsibilities into their lives. To enhance collaboration between caregivers and professionals in the short term, care organisations and social and healthcare educational programmes should encourage a professional mindset that recognises caregivers as equal partners in care. It is essential for professionals to acknowledge the caregiver’s role and devise strategies for arranging care together that build on the existing relationship between the caregiver and care recipient.

## 1. Introduction

Collaborating with informal caregivers (In this article, the authors label family members, friends, neighbours, or other close contacts who provide informal care to someone with long-term care demands such as intellectual disabilities, psychiatric problems, chronic illness, or age-related problems as “caregivers,” regardless of whether the care recipient lives independently or residentially.) in a relationship of

equality to support care recipients is a competence that is becoming increasingly important for social and healthcare professionals [1, 2]. The Netherlands, like several other countries, is working to revise long-term care policies to meet the increasing demand for care [3]. Several care responsibilities have shifted from national to local authorities, and both national and local authorities are working to shift care responsibilities from formal to informal care providers [4]. The growing dependence on caregivers, coupled with

local authorities and health insurance companies being strongly urged by the national government to ensure that care recipients live at home for as long as possible [5], fundamentally underpins the increase in interactions between caregivers and professionals. In residential settings, there is an increasing expectation for interactions between caregivers and professionals as well, as care organisations increasingly rely on the help of caregivers [6]. Consequently, social and healthcare professionals are increasingly expected to actively involve, support, and collaborate with caregivers [2]. Unfortunately, the standards for collaboration between professionals and caregivers are not yet established. Social and healthcare professionals often focus solely on care recipients. Therefore, collaboration can be complex, and it is often challenging to establish effective collaboration [7, 8]. In addition, there is a growing understanding that individual caregivers' context should be considered in professionals' approaches to collaboration [9–11]. For example, caregiver satisfaction with professional care differs between various groups of caregivers [12–14]. Thus far, little is known about the role of diversity in caregivers' preferences regarding collaboration [11].

Collaboration between caregivers and social and healthcare professionals is a dynamic and interactive process of sharing perspectives, responsibilities, partnership, interdependency, and power [15]. The existing research on factors that hamper and strengthen effective collaboration in informal care situations has found that most issues relate to the pursuit of trust [8, 16]. This may regard trust in the *organisational context* in which care is provided and trust in the *relationship between caregivers and professionals*.

First, collaboration may be hampered by the organisational context in which care is provided. The Dutch care system (the phrase “Dutch care system” refers here to the organisation of both health and social care) and concerns about the accessibility of care within this system are described in Figure 1, which is explained in the Appendix. Within this system, professionals may feel restricted by the organisational structures and stakeholders that influence collaboration [7]. For example, social and healthcare professionals have a legal obligation to care recipients but less to caregivers. For example, in the Health Insurance Act, there is no explicit mention regarding collaboration with caregivers [5]. Thus, professionals may not have available time to connect with caregivers [17]. Taking time to build trust is essential, yet professionals often find themselves conflicted between prioritising the needs of care recipients and those of caregivers [18, 19]. Ambiguity and frustration among care recipients and caregivers due to the complexity of the care system [20] may also influence the relationship between professionals and caregivers, as professionals must operate on the border of this system and caregivers' experiences and face the difficult task of connecting these two worlds [21].

Second, collaboration may be hampered by the relationship between the professional and the caregiver. For example, in how professionals communicate their expertise, such as exhibiting an authoritative or directive demeanour, rather than adopting a partnership approach. This may complicate collaboration as such an approach can create a power imbalance that prevents caregivers from

being recognised for their own expertise [7, 8]. Difficulties in communication, uncertainty about what information to share with caregivers, and differences in views on the division of responsibilities are all factors that hamper effective collaboration [22, 23]. Professionals who acknowledge the importance of the role of caregivers and keep an open, proactive, and compassionate attitude can improve collaboration [24, 25]. It is important that professionals and caregivers become partners in care, even though engagement with professionals can be difficult and stressful for caregivers [10, 26]. Having informal communication and a personal connection increases trust and helps caregivers feel involved as equals in decision-making [16, 17]; however, such collaboration is difficult to implement in practice.

Thus far, little is known about the role of diversity (e.g., gender, age, and cultural background) in caregivers' preferences regarding these collaborations [11]. Studies have found that diversity plays a role in underlying expectations, values, norms, assumptions, and behaviours regarding informal care [26, 27, 28, 29]. Researchers have also found differences between groups of caregivers based on their social position, such as gender and cultural background, regarding their satisfaction with professional care [12–14]. There is growing evidence that a “one size fits all” approach to connecting with caregivers is not effective, particularly when that approach lacks consideration of the context in which informal care is provided [10, 26, 29]. The need for diversity-sensitive measures in informal care research has been emphasised by scholars, and several have proposed the adoption of an intersectional approach in future research [11, 27, 30, 31, 32]. The added value of an intersectional approach is that it moves beyond single categories (or “social positions,” such as gender, age, and socioeconomic status) to consider the interactions between different aspects of social identity and the impact of systemic and power dynamics in care collaborations [29, 33, 34]. An intersectional approach can be helpful to give voice to the multidimensional and relational nature of caregiving and the social conditions within which care is provided [30]. This approach also has the potential to offer insight into the relationship between caregivers' experiences, social identities, and society, as well as differences between and within groups [4, 11]. In this article, we therefore adopt an intersectional approach. The research question is twofold: (i) To what extent do opinions among caregivers with diverse backgrounds differ regarding collaboration between themselves and social and healthcare professionals? (ii) What is the influence of caregivers' intersecting social positions, as well as the impact of systemic and power dynamics on these opinions? The aim of this qualitative study is to generate knowledge about the extent to which intersecting social positions of caregivers translate into their preferences regarding collaboration with social and healthcare professionals and about the impact of systemic and power dynamics on these collaborations.

## 2. Methods

Intersectionality has a constructivist stance, putting the lived experience of individuals at the centre of analysis [35, 36].

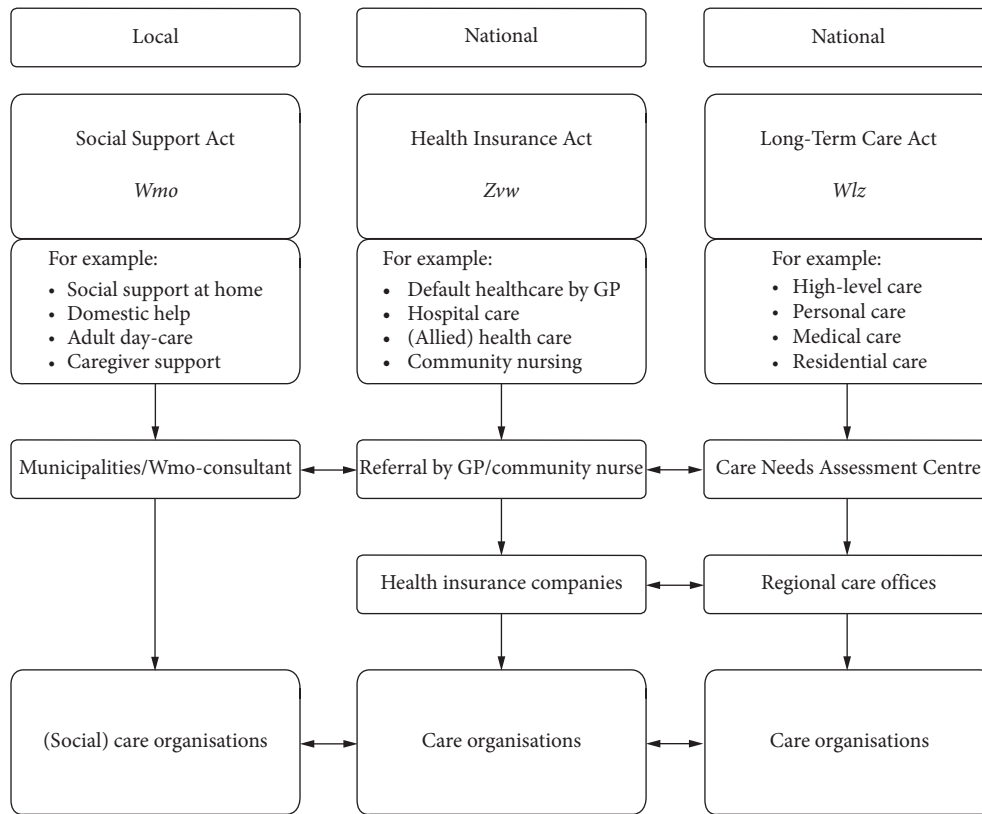


FIGURE 1: About the Dutch care system.

This requires a research strategy that respects differences between people and offers the opportunity to grasp the subjective meaning of social action. Qualitative research methods are suitable for achieving this. The study presented in this article is part of a broader qualitative research project. It relies on the methods described by Wittenberg and colleagues [26]; thus, the description of methods in this article partly reproduces their wording. Focus groups were organised to discuss caregivers’ views on collaboration with professionals. Small groups of respondents were interviewed by a moderator, using a group process to stimulate discussion and obtain information regarding the beliefs, attitudes, and motivations of respondents on collaboration between caregivers and professionals [35].

**2.1. Data Collection.** Respondents were recruited by advertising through Dutch care and informal care support organisations, including Cordaan, Amsta, Combiwel, Markant, and Platform Mantelzorg in Amsterdam, the Netherlands. In addition, calls for participation were shared on several social media platforms, including LinkedIn. Caregivers could participate if they were at least 16 years old and provided long-term care for someone with a physical or mental disability. In the calls, we wrote some examples to clarify this: “Think of chronic illness, a form of dementia, Acquired Brain Injury, intellectual disability, psychosocial problems, or a disease such as schizophrenia.” It did not matter whether the care recipient lived independently (with

or without the caregiver) or residentially. We aimed to attain a relatively representative sample within the population of interest, while being heterogeneous enough to allow for (partially) inductive explorations [37]; thus, we asked consultants allied with Mantelzorg Steunpunten Amsterdam to contact caregivers who might not otherwise see the call to participate in the study. Respondents received written study information, and participation was elective. Data collection was in strict accordance with the Dutch national standard.

To be able to consider caregivers’ social positions and analyse relevant intersections of the characteristics of diversity and context in relation to caregivers’ views on collaboration, all respondents were interviewed individually prior to the focus groups and asked about their own background, the background of the care recipient, and the care situation. In total, 37 caregivers were interviewed individually, either face-to-face or by phone. Interviews typically lasted approximately 30 minutes.

After the individual interviews, all respondents were invited to attend a focus group. The data for this study were collected between November 2019 and June 2020. During data collection, the COVID-19 pandemic began, which necessitated an adjustment of the research methods. A total of eight focus groups were conducted, four of which were face-to-face in December 2019 and January 2020. The other four focus groups were conducted online via Zoom in May 2020. In total, 30 of the 37 respondents joined one of the focus groups. The remaining respondents did not join due to practical reasons (e.g., because they had no time due to the

needs of their care recipient). Each focus group consisted of two to five respondents and lasted for about 2 hours.

In the focus groups, caregivers were asked to elaborate on their preferences regarding collaboration with social and healthcare professionals. We also discussed whether professionals considered the caregivers' personal and contextual background and care attitudes during collaboration. Data collection was based on an intersectionality-informed approach. Questions that frame social categories as separate were avoided, and questions that were included had a broad focus on day-to-day experiences [41]. For example, one question asked: "Do professionals also pay attention to your background, for example, the fact that you are a retired man or woman, or a woman with German or Indian roots?"

Six social work students were involved in data collection. They conducted several individual interviews and were present during some focus groups to support the lead author, who moderated the discussions. Students were trained and supervised by the lead author during the data collection process.

In recognition of the mental and emotional burdens associated with caregiving, the moderator and social work students offered respondents an opportunity to talk privately after the focus group. In addition, information about available support for caregivers was offered in collaboration with a local caregiver support centre. These conversations were not recorded and analysed.

**2.2. Analysis.** All interviews and focus groups were audio recorded and transcribed verbatim, and respondents were anonymized. At no time did the dataset contain direct identifiers. Qualitative content analysis was then conducted using a directed approach [38]. First, we used predetermined codes based on a previous study of caregivers' judgements about sharing care with professionals [14]. Questions and statements from this quantitative study, which we also presented to the respondents in this qualitative study, have been transformed into codes with which the data were initially analysed. Examples of these codes are discussing worries, consideration for caregivers, disagreements, and what brings (dis)satisfaction. Second, any text that could not be categorised within the initial coding scheme was assigned a new code using open coding. Third, we reflected on the specific role of intersecting diversity characteristics in caregivers' views and added codes that specified these diversity characteristics. Finally, we reassessed the coding scheme to make connections across the data and provide a deeper explanation of relevant phenomena [37]. We used an intersectional approach to move beyond a focus on separate categories of difference and towards a focus on how social categories interact. This approach enabled us to better reflect the views and experiences of involved caregivers [37].

Coding was conducted by the lead author in consultation with the second author to increase credibility. To begin, all quotations were read by the first two authors, and the main themes were discussed. Next, about 20% of the data were coded by the lead author, and the resulting codes were discussed with the second author, leading to several adjustments in the coding scheme. The remaining data were

then coded by the lead author, after which the second author checked all applied codes for consistency. The final coding scheme is presented in Table 1.

At the end of the study, respondent validation was conducted to confirm that the research findings were congruent with the respondents' views on the subject [35]. All respondents were offered the opportunity to read and respond to the final version of the article. No respondents objected, and one respondent explicitly agreed with the study conclusions.

### 3. Results

Information about respondents' backgrounds, the backgrounds of the care recipients, and the care situations is summarised in Figure 2, based on the visualisation of dimensions of diversity in informal care research presented by Hengelaar and colleagues [11]. Except for three respondents, all other caregivers were part of a care situation in which at least one social or healthcare professional was involved to help either the care recipient or the caregiver.

Professionals included individuals who provide care at home or residentially, such as home care professionals, community nurses, GPs, or social workers. The three respondents who were not involved with professionals did not answer the questions about collaboration with professionals in the individual interviews. However, they did participate in the focus groups, allowing them to reflect together with the other participants on their preferences regarding possible future collaboration with professionals. Many respondents who did have contact with professionals generally found it difficult to say whether they were satisfied with the collaboration, because they were in contact with several professionals at once, and their satisfaction differed by professional and over time. Nevertheless, a small majority of respondents were predominantly positive about their collaborations with professionals. An overview of the main themes and subthemes can be found in Table 2.

The factors that hamper and strengthen effective collaboration in the organisational context in which care is provided and in the relationship with professionals are discussed in the next section.

**3.1. Organisational Context.** Most of the dissatisfaction caregivers expressed about collaborating with professionals was related to the organisational context in which such collaborations occurred. For example, respondents expressed dissatisfaction with the complexity of the care system and the procedures and bureaucracy within it, problems within care organisations, and the quality of care provided by professionals.

**3.1.1. Complexity of the Dutch Care System.** Respondents noted that it is becoming increasingly difficult to arrange professional care for the care recipients they are helping. Some find it so difficult to organise help that they feel desperate and decide to provide the needed care themselves, whereas others feel they have to "fight" to get needed care.

TABLE 1: Coding scheme.

Coding scheme	Quantity
Caregivers' judgements	
Discussing worries	37
Consideration for caregivers	78
Attention for caregivers' background	24
Disagreements	41
What brings satisfaction	
Being seen	6
Quality of care	9
Professionals' attitudes	21
Sharing care	15
What brings dissatisfaction	
Lack of quality of care	51
Flawed communication	13
Lack of continuity	13
Bureaucracy and procedures	51
Effect of changing welfare state	55
Expectations towards professionals	
Professionals' attitudes	35
Being seen	18
Professionalism and organisation of care	33
Flexibility	8
Sharing care	21
Expectations of the government	117
Caregiver diversity characteristics	
Gender	18
Age	21
Health	8
Religiosity	12
Own identity	12
Financial situation	8
Employment	41
Care recipient diversity characteristics	9
Contextual characteristics of diversity	
Ethnicity/culture	49
Family situation/upbringing	53
Living environment	9
Physical proximity between caregiver and care recipient	18

Respondents find the care system to be complicated, and several respondents shared their difficulties getting a referral to the right type of help or care. There is often a lot of paperwork, applications can take months to process, and sometimes must be completed multiple times, and there are long waiting lists for some types of support. Respondents also described concerns about the rigidity of rules and the need for more flexibility and adaptability within the care system for the benefit of the care recipient or caregiver. The perceived complexity of the care system leads caregivers to feelings of dissatisfaction and helplessness. Some respondents also reported feeling that the government operates on the basis of distrust rather than trust, the government holds too much control, and the perspective of human dignity is lacking in the care system.

Several caregivers noted that they would like the government to acknowledge informal care as an important part of the care system. They feel that authorities are unable to empathize with the provision of informal care, because they do not understand the burden of providing such care. Some

respondents reported that caregivers are not heard enough, with one respondent calling to *“Talk with us, instead of just talking about us”* (FG2, R11, ♀ 30). Respondents felt that the government should give voice to caregivers and invest in them.

Several respondents indicated that there is poor coordination between different care organisations, which may prevent some people from receiving the needed care. However, respondents also reported that care organisations try to transfer responsibilities to other parties, as some respondents were referred to other care providers multiple times. According to respondents, care is fragmented and commercialized, and the procedures and provision of care can vary by municipality. One respondent described: *“Especially now with the decentralisation of care towards municipalities, you have to be some kind of expert, because (. . .) things are arranged differently, and then you get into a whole maze of rules (. . .). And for one thing, you have to be with the municipality; for the other, you have to be at another counter, at another organisation. That doesn't make it any clearer”* (FG7, R26, ♀ 36).

Within the Dutch care system, caregivers can receive direct support arranged by municipalities, under the Social Support Act (see Figure 1). However, few respondents use this type of support, and it is a source of dissatisfaction for some. Respondents mentioned that much of the direct support is specifically aimed at caregivers for older adults and not, for example, at parents who provide informal care to a child. Others feel that the offer of support is designed to frame caregivers as “victims,” which is not a supportive framing. Some respondents feel that the offer misses the mark completely and is inappropriate, and some stated that if the government expects people to provide informal care, they should facilitate it through other life domains, such as: *“By calling on employers to be informal care-friendly employers. By saying schools to pay attention to young caregivers. By making provisions in public transport and, wherever, for people with chronic conditions”* (R4, ♂ 32).

**3.1.2. Problems within Care Organisations.** Respondents expressed dissatisfaction with care collaboration because of professionals' need to operate within the rules and procedures of their own organisations. For example, some respondents felt that professionals adhered too strictly to protocols, which creates a negative environment in which caregivers must negotiate for the care recipients' needs. Respondents would appreciate increased flexibility and would like professionals to try to help instead of stating that something is not possible based on protocols. Privacy legislation—that prohibits sharing information on people older than 18 (being themselves adults by then)—was also mentioned as a problem for parents who provide care to a child who is 18 years of age or older but still in need of care because of, for example, intellectual disabilities. Contact with professionals sometimes remains superficial then, or it can be difficult for the caregiver to assist the care recipient in seeking the right help or support due to privacy regulations. *“As a mother, that really makes me sick to death, because it is determined for you in the privacy legislation, and you are not*

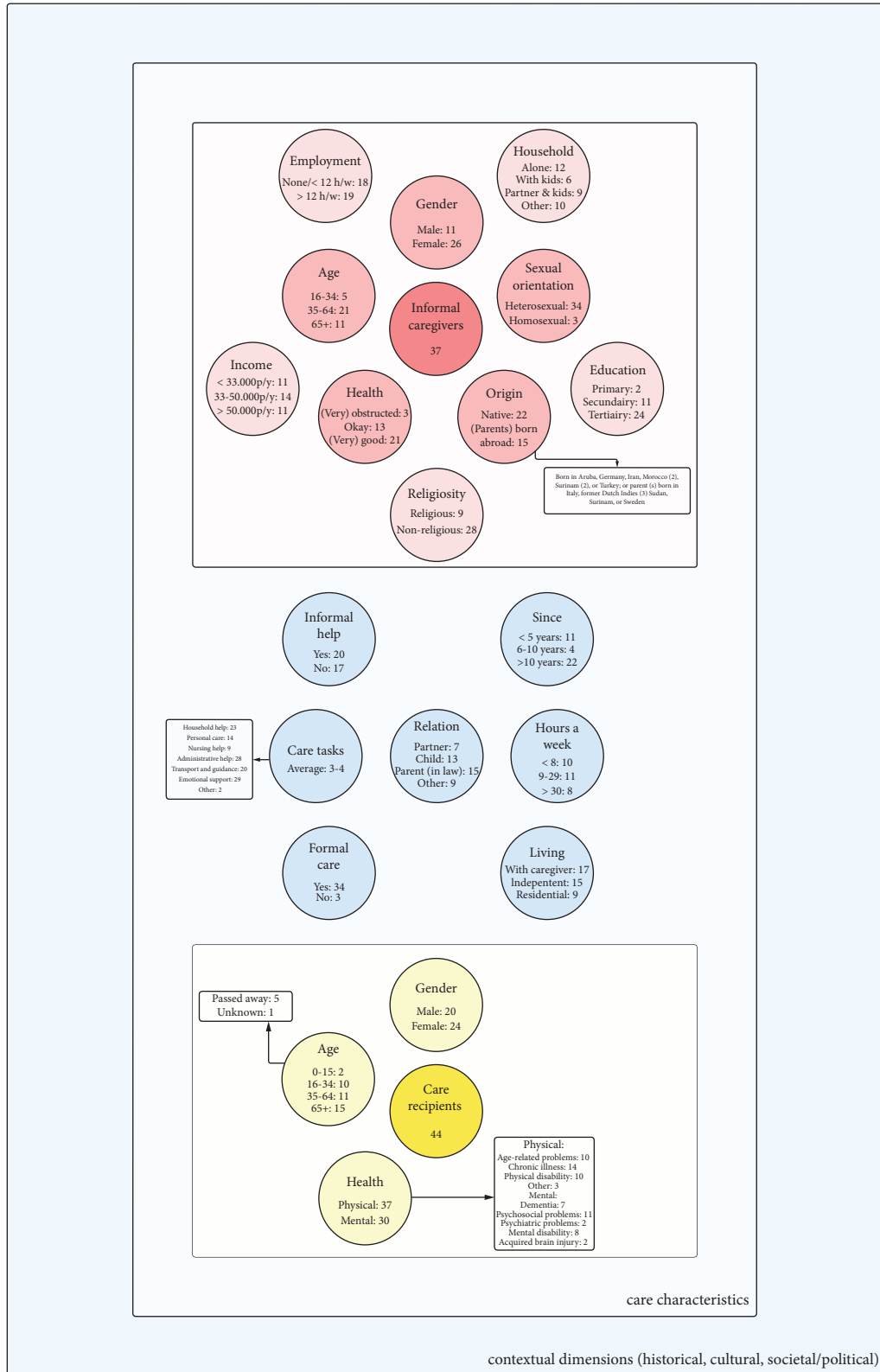


FIGURE 2: Diversity in respondents' care situations.

asked what you want. How you want to [organise] it for you and your child. I find that very annoying" (FG4, R24, ♀ 55).

Some respondents stated that help has become less personal over time due to the scaling up of care

organisations. Several respondents indicated that it can be difficult to contact organisations or individual professionals. They often have a poor response time for emails or messages via digital tools. Others indicate that they must search for

TABLE 2: Overview of main themes and subthemes.

Main themes	Subthemes
Organisational context	Complexity of the Dutch care system
	Problems within care organisations
	Quality of care provided
Relationship between professionals and caregivers	Recognising the caregiver
	Considering the caregiver's background
	Professionals' attitudes

information and ask for appointments themselves, which could be interpreted as disinterest towards the caregiver.

**3.1.3. Quality of Care Provided.** Respondents also expressed dissatisfaction because of problems with the provided care, such as unkept promises, medical mistakes, care that does not fit the care recipients' needs, and disappointing care in practice. Some respondents referred to care in residential settings as "chaos." Consequently, some caregivers feel they could not turn over caregiving responsibilities to residential care facilities even if they wanted to, and feel they must keep providing it themselves. Several respondents indicated that they would like organisations to be more demand-oriented in their work and be responsive to the needs of care recipients and caregivers to provide high-quality care that matches the needs. In that case, it would be particularly important for caregivers to maintain control of the care situation. One respondent stated: "*People always have the feeling that they lose control, that someone takes over, and you have nothing more to say. People think the risk is too big that things then don't go the way they would like it. So they'd rather not do that*" (FG6, R30, ♀ 69).

Finally, frequent changes among staff were a significant source of dissatisfaction for respondents. Most respondents reported seeing many different changes in care professionals, as well as at the management level. These changes are not always communicated to caregivers, leaving them unclear about who is responsible for the care recipient. Communication between outgoing and incoming staff is often lacking as well, which leads care recipients and caregivers to have to tell their stories repeatedly. An annoying and burdensome experience. One respondent stated: "*I also have that experience with a lot of changes among staff; someone left five years ago and there are already six [others] and then you have.. Then I think, "Gosh, we discussed this" and then it's like "I don't know anything about that" and then you can start all over again, and that makes you so despondent*" (FG3, R8, ♀ 68). Some caregivers mentioned that because they see so many new faces all the time, they lose trust in professionals. They would like professionals to show long-term commitment and record agreements so that new colleagues can inform themselves accordingly.

**3.2. Relationship between Professionals and Caregivers.** Respondents shared several factors that hamper and strengthen their relationships with professionals. They reported that recognising the caregiver and considering the caregiver's background is important. However, most of the

factors mentioned by respondents were related to professionals' attitudes towards caregivers and care recipients.

**3.2.1. Recognising the Caregiver.** A vast majority of respondents stated that professionals pay little to no attention to how the caregiver is doing and focus solely on the care recipient. It is not common for professionals to ask questions about what caregivers are doing for care recipients or how caregivers are doing themselves. Respondents would prefer professionals to ask these questions for several reasons. First, doing so could improve the relationship between professionals and caregivers, which could lead to better care for the care recipient. Second, asking questions about the caregiver may lower the caregivers' threshold for raising concerns and offer professionals the opportunity to understand the burden caregivers experience. Overall, respondents shared that they want to be listened to and appreciate professionals who care for the caregiver as well. One respondent noted: "*That feels incredibly well, but I nearly fell off my chair when someone said that. That still stuck with me, that I was like, "Gosh, what a nice woman you are." But you rarely come across that*" (FG7, R34, ♀ 62). Respondents stated that the professionals' interest must be sincere, and professionals should act on the information and wishes expressed by caregivers. Respondents who were satisfied about their contact with professionals shared that they were happy that professionals responded well to their requests or took time for caregivers during conversations about the care situation.

It was more common for caregivers to report that professionals paid attention to them or that they could easily share their concerns when professionals had been involved in the care situation for a long period of time or when professionals were hired by the caregivers themselves (e.g., using a personal healthcare budget [PGB]). Long-term contact ensures people can get to know each other and build a relationship of trust. Not all respondents knew who to contact to share their concerns due to high staff turn over among professionals, and they found it challenging to build strong relationships with these short-term contacts.

**3.2.2. Considering the Caregiver's Background.** Respondents reported that professionals spend little attention on getting to know about caregivers as people and the context in which they provide informal care. Several respondents stated that professionals seemed to have little regard for who the caregiver is and what they do aside from providing informal care. Considering the caregiver's background can make it easier for the professional and caregiver



to discuss concerns. For example, respondents stated that it is important for professionals to know whether the caregiver is employed or studying in addition to their caregiving tasks. One respondent explained: *“If you work full-time and you also have many hours of informal care to provide daily, and maybe you also have a limited social network, then there is a greater risk to become overburdened”* (FG7, R26, ♀ 36). It would also be helpful for professionals to understand factors related to the caregiver’s gender and age, as well as whether the caregiver has children. For example, a young woman who has children and a job may find it difficult to combine these responsibilities with providing informal care. It may be particularly difficult for this caregiver to ask for help from professionals, because the help needed may be due to the burden of working, having to care for one’s own children, and providing informal care rather than the caregiving tasks.

Learning about the caregiver’s cultural background was also mentioned as an important factor. One respondent with Turkish roots explained: *“Also for certain, let me call it “Western ways” of talking openly about death and things like that, which do not always fit within Turkish culture (. . .). Sometimes I have mentioned that, like, Gosh, in Turkish, I cannot ask this [to my father]. Or, “this is a very difficult question you are asking.” But that is something that could possibly be [taken more into] account”* (FG8, R35, ♂ 42). Some respondents noted that it is also important for professionals to understand the role of religiosity in care situations, such as in conversations about death and euthanasia. Finally, respondents noted that caregivers who are ageing may become less able to help over time. In these cases, professionals could help caregivers ask their wider social network for help.

Although caregivers would prefer professionals to pay more attention to them overall, several respondents felt that the lack of attention is acceptable if they are satisfied with the quality of care provided to the care recipient. As one respondent expressed: *“I think the most important thing is that the care and attention goes out to the care recipient. (. . .) If you feel that is not happening enough or not well enough, I think professionals should leave the attention for the caregiver for a while and focus on those who need care”* (FG8, R27, ♀ 47).

**3.2.3. Professionals’ Attitudes.** Respondents indicated that it is important that professionals take caregivers seriously, show respect, and view them as equal partners in the care situation. Several respondents said they would like professionals to start by understanding the caregivers’ experience with the care situation. After sharing these experiences, the professional and caregiver can build a plan to arrange care together in which clear agreements are made about the division of tasks. Some respondents stated that digital tools can help caregivers communicate about these agreements. For example, an app or digital environment where caregivers and professionals can schedule appointments and divide tasks together. Overall, respondents want professionals to organise and provide care together with them, in an equal partnership in which all involved parties feel seen and heard.

Respondents mentioned several attitudes that would help improve collaboration. For example, they stated that it is important for professionals to be open, approachable, present, kind, flexible, proactive thinkers, no-nonsense, firm, and clear. Respondents preferred professionals who can listen and be there with a smile; show understanding, empathy, and respect; be involved; be reliable; and do what they have promised. One respondent stated: *“It is not about the care tasks they have to do, it is about how kind they are”* (FG6, R33, ♀ 56). Several caregivers mentioned that it is important to have a good connection between themselves and professionals, and both parties must invest in this relationship.

Several respondents stated that professionals should be careful not to make assumptions about caregivers based on their background. For example, several female respondents shared that professionals assumed they would take on certain informal care tasks because they were women, or, in some cases, because they were the care recipient’s daughters. In addition, professionals may incorrectly assume that a caregiver with a migration background wants to help in certain ways. One respondent explained that in some cultures, it is embarrassing for a father to need physical help from his son. Some respondents mentioned that within Moroccan and Chinese communities, people may feel ashamed to ask for help, and they felt professionals should be mindful of those cultural differences. One respondent highlighted this point: *“I would like to mention the Moroccan origin again, for example, then [professionals] have to know a little bit how to deal with that. So it becomes easier for that [caregiver] to talk about frustrations they encounter. And sometimes, language is also a problem”* (FG4, R24, ♀ 55). Finally, some respondents noticed that professionals tend to provide more help to caregivers who are in poor health themselves. However, caregivers who are healthy may still need help in providing informal care, as combining caregiving with other life domains can be burdensome.

Some respondents who reported dissatisfaction in their collaboration with professionals indicated that their dissatisfaction related to professionals’ attitudes. For example, collaboration is hampered when professionals view their tasks as “just work,” or when caregivers perceive that professionals would rather do as little as possible. If a professional refuses to do something because it is not part of their established tasks, this refusal may harm the caregivers’ trust in the professional. According to some respondents, it hinders effective collaboration when professionals are not open to caregivers’ suggestions or expertise to improve care. Finally, dissatisfaction with collaborations can arise when caregivers perceive a lack of knowledge among professionals related to treatment or support options or specific care conditions. Some respondents would like professionals to be more open to learning about the specific care situation. As one respondent expressed: *“And that they say it, “I don’t know.” And “Shall we figure it out together” or something. And don’t come up with a lousy talk. (. . .) We had very good experiences with [professionals] who were curious about (. . .) our children. And who had no knowledge, but started looking at [our children] as a person”* (FG4, R3, ♀ 48).

## 4. Discussion

The aim of this qualitative study was to generate knowledge about the extent to which intersecting social positions of caregivers translate into their preferences regarding collaboration with social and healthcare professionals and about the impact of systemic and power dynamics on these collaborations. During the interviews and focus groups, many respondents actually described the problems they encountered in collaboration, rather than what they would like to experience in collaboration. The findings reveal that most dissatisfaction concerning such collaborations does not stem from the interactions between caregivers and individual professionals. Rather, caregivers' concerns about collaboration are often rooted in the organisational context within which their interactions with professionals occur. Concerns about the complexity and accessibility of the Dutch care system have been widely acknowledged [20, 39, 40]. According to caregivers who participated in this study, the complexity of the system makes it challenging for them to coordinate suitable help and care for both care recipients and themselves. These challenges lead to frustration and a sense of helplessness. The examples respondents provided include issues related to appropriate referrals, protocols that create a need to negotiate for provided care, and frequent staff changes that erode caregivers' trust in professionals. These examples illustrate that it is predominantly the system itself that hampers effective collaboration between caregivers and professionals. If a particular care situation does not "fit" within the care system, tensions and conflict may arise [29]. This finding is concerning, because in most caregiving situations, assistance is only requested from professionals when the need for care is substantial, and there is already considerable pressure on the caregiver.

The role of diversity in caregivers' preferences regarding collaboration with professionals as well as the impact of systemic and power dynamics on these collaborations was also explored. Caregivers in this study reported that they prefer a relationship of equality with professionals characterised by trust. They want to feel heard and have professionals take time for caregivers as well as care recipients. Such characteristics are best supported within long-term relationships. Caregivers find it easier to express concerns if professionals know them, understand what they do for the care recipient, and understand what they do besides providing informal care. Other studies also showed that creating a personal connection and investing in effective collaboration can increase trust and ensure caregivers feel involved as equals in decision-making in the short term [8, 16] and improve the quality of care in the long term [13]. Effective collaboration with caregivers may also lead to a decreased workload for professionals [7, 41].

Interrelated social positions, such as gender, age, whether someone has children, and employment status, play a role in how easily someone can fit informal care into their life and sustain caregiving tasks over time. Caregivers reported that it is not only the severity of the care recipient's needs that determines whether the caregiver

requires assistance but also the caregiver's own background and the context in which informal care is provided. Caregivers urge professionals to be sensitive to the context of informal care provision and caregivers' beliefs about such care provision (e.g., based on their cultural background or religiosity). It is also important for professionals to avoid making assumptions about caregivers based on their social position. In practice, however, professionals pay little attention to caregivers, their backgrounds, and the context in which they provide care. This lapse may be due to protocols within organisations or high workloads that prevent professionals from investing in effective collaboration with caregivers. Ideally, caregivers would prefer professionals to organise and provide care together with them in an equal partnership in which all parties feel seen and heard.

The study findings indicate that diversity in caregivers' social positions does not necessarily lead to different opinions about what is important in collaboration with professionals. Across social contexts, caregivers want professionals to consider their social positions, which determine the context in which informal care is provided. This finding provides a nuance to the existing knowledge about the role of diversity in collaborative relationships between caregivers and professionals. Although prior studies have found indications that caregivers' social positions contribute to differences in satisfaction with professional care [12–14], the current study findings indicate that caregivers' preferences for collaboration are shared in common. The results also indicate that a "one size fits all" approach to connecting with caregivers would not be effective [10, 26, 29], because caregivers want professionals to be sensitive to their interrelated social positions and, therefore, the context in which informal care is provided.

*4.1. Strengths and Limitations.* The intersectional study approach helped the research team to focus on the role of social positions of caregivers and the impact of systemic and power structures [29, 33, 34] on caregivers' experiences with collaborations with professionals. In this study, the intersectional approach did not reveal differences in caregivers' wishes regarding collaboration with professionals. However, it did enable an exploration of how and why caregivers prefer professionals to consider their social positions during collaboration, as well as the impact of systemic and power structures on collaboration. The results reveal that caregivers have a sense of powerlessness regarding their ability to organise collaboration with professionals to provide added value and satisfy all parties involved.

This study also has some limitations. All respondents had to be able to communicate in Dutch. In addition, nearly all respondents had already utilised some form of professional assistance (e.g., from a community nurse). Given the relatively large number of well-educated respondents in the study sample, we can deduce that we primarily engaged with individuals who demonstrated the ability to seek and arrange help for their loved ones and/or themselves. Consequently, our research may have excluded a potentially vulnerable

group of caregivers who are unfamiliar with the existing support systems. This has consequences for the transferability of findings. Because we did establish credibility by conducting analysis with two researchers and respondent validation, we do however think results of this study are trustworthy [35].

Another significant research challenge was the need to adapt our research methods due to the COVID-19 pandemic. Half of the focus groups were postponed and subsequently conducted online. To ensure the quality of our research, the lead author reviewed the methodology and studied examples of online audio-visual focus groups. This review led to the decision to furnish respondents with comprehensive pre-focus group guidance that provided tips for technology usage and session ground rules. The aim of the guidance was to enhance the stability of group participation rates and mitigate potential technical issues and distractions during the sessions [42]. Despite implementing these measures, the group sizes were somewhat smaller than the face-to-face focus groups, and sessions were occasionally disrupted due to technical issues. During the data analysis process, both the lead and second author assessed the richness of data generated in the face-to-face and online focus groups. Respondents in the online focus groups displayed less interaction with others and were less inclined to interrupt discussions. These findings align with findings from other studies that have compared focus group methods [43]. However, data collected during the online focus groups were still in depth and, by our judgement, reliable for helping to answer the research questions. The conversations were generally about the care situations caregivers were involved in and not specifically related to the COVID-19 pandemic. In some conversations, respondents briefly discussed the difference between providing informal care during the pandemic and before. Since this was only a small part of the conversations and was not part of our research questions, it was decided not to include this information in our analyses.

## 5. Implications for Policy, Practice, and Research

Dutch organisations that advocate for both formal and informal caregivers and care recipients (such as V&VN, <https://www.venvn.nl>; MantelzorgNL, <https://www.mantelzorg.nl>; and Patiëntenfederatie Nederland, <https://www.patiëntenfederatie.nl>) have increasingly appealed to political parties and policymakers to eliminate obstructive regulations and procedures and operate on a foundation of trust instead of distrust. Our study results are aligned with this call, as several respondents advocated for these factors in the focus groups. We want to add that policymakers and health insurance companies should promote and facilitate time for professionals to be able to invest in effective collaborative relationships with caregivers [26]. Furthermore, aspects related to informal care could, for example, be incorporated into care assessment procedures that determine what professional assistance care recipients can receive.

Caregivers noted that help has become less personal due to the scaling up of care organisations. Cooperation among

organisations can prevent people from falling between the cracks. By taking a demand-oriented work approach, being easily accessible, and ensuring effective communication among professionals, organisations can treat care networks in a respectful manner and better satisfy the needs of caregivers.

It is also important for organisations to improve their approach to direct support for caregivers, as many respondents felt that the current offer is inappropriate. Caregivers should be acknowledged for their strengths and knowledge about specific care situations, and offers of direct support should better meet caregivers' needs, especially for those who provide care to people who are not older adults. The respondents in this study urged the government to provide mechanisms to better integrate informal care into other aspects of their lives. As in one of our previous studies, we advise national and local policymakers to encourage relevant partners, such as employers, to facilitate the combination of informal care with other life domains, such as employment or parenting [26].

The Dutch care system arrangement is a political matter that individual professionals cannot directly alter. However, individual professionals have an opportunity to enhance caregivers' satisfaction with collaboration through the attitudes they adopt, as the caregivers in this study called for open, kind, proactive, involved, and reliable professionals. Caregivers in this study also expressed that they prefer professionals to be sensitive to their interrelated social positions and the context in which informal care is provided, as these factors influence the way they can and want to provide care. Social and healthcare educational programmes should emphasise the importance of these attitudes among professionals. Effective collaboration with caregivers requires specific competencies [1] and a mindset in which caregivers are acknowledged and treated as equal partners, which new professionals should learn from the very start of their career.

Future research about informal care provision should continue to focus on the role of caregivers' social positions and the context in which informal care is provided. This research direction provides information about differences between caregivers, situational circumstances that influence their capability to provide informal care, caregiver burdens, and the ways caregivers would like to collaborate with professionals. Furthermore, the research revealed that it was more common for caregivers to report that professionals paid attention to them or that they could easily share their concerns when professionals were hired by the caregivers themselves. It would therefore be interesting to investigate whether there are more differences in experiences between people who do or do not receive a personal healthcare budget. Finally, future research on how to improve the Dutch care system should include voices of care recipients and caregivers, as suggested by the Council of Public Health and Society as well [44]. It is important to include these voices in the conversation to understand their needs and values, assess the impact of policies, and create public support for future care system improvements.

## 6. Conclusion

This study shows that opinions among caregivers with diverse backgrounds regarding collaboration between themselves and professionals do not necessarily differ. Most of caregivers' worries about collaboration with professionals are rooted in the organisational context within which these interactions occur, which often results in a feeling of helplessness. Caregivers prefer a relationship of equality with professionals characterised by trust. Also, caregivers in this study appeal to policymakers to eliminate obstructive regulations and procedures from the care system and function on a foundation of trust instead of distrust. Nevertheless, the organisation and conditions of the care system are political matters that cannot be directly altered by caregivers or professionals. To enhance the quality of collaboration between caregivers and professionals in the short term, care organisations and social and healthcare educational programmes should encourage professionals to embrace a mindset wherein caregivers are acknowledged and treated as equal partners. Care organisations should invest in improving staff turnover rates and facilitate time for professionals to create enduring relationships with caregivers. Across social contexts, caregivers want professionals to be sensitive to their interrelated social positions and the context in which informal care is provided. This context shapes caregivers' capabilities and intentions in caring for their loved ones and determines whether they require assistance in sustaining caregiving tasks. Individual professionals can amplify effective collaboration with caregivers by exhibiting openness, kindness, proactiveness, engagement, and dependability. Finally, it is critical for professionals to recognise the caregiver and devise a strategy for arranging care together that builds on the existing relationship between the caregiver and the care recipient.

## Appendix

In the Netherlands, 342 municipalities are responsible for enforcing the Social Support Act. Caregiver support, such as respite care, is arranged through this Act, and caregivers are also indirectly supported by the help offered by social and healthcare professionals to care recipients. Under the Health Insurance Act, private health insurance companies play a key role in organising care in a system based on regulated competition. The Long-Term Care Act governs high-level and (most) residential care throughout the Netherlands. People in need of care must apply for an assessment at the Care Needs Assessment Centre (CIZ), and regional care offices organise care based on the assessment outcomes [45]. The Netherlands also maintains the Youth Act, which makes local authorities responsible for youth care for individuals under the age of 18. The number of care recipients younger than 18 is limited in this study; therefore, this act is not included in Figure 1.

Under all acts depicted here, people can choose whether to receive care in kind (i.e., authorities determine which care organisations people can choose from) or organise care themselves out of a personal healthcare budget (PGB). The

social insurance bank (SVB) is responsible for the payment of personal healthcare budgets. Independent client supporters can help people organise care. Due to the complexity of the Dutch care system, care recipients and caregivers may be in contact with several professionals at the same time, depending on type and severity of the needed care. Contact between referrers, such as municipalities, GPs, or the Care Needs Assessment Centre, is not self-evident due to privacy legislation but may sometimes occur with specific permission from the care recipient.

Although the Dutch care system is one of the world's best, concerns about the accessibility of care within this system are increasing. Care recipients do not always receive the care they need due to scarcity, rising costs, workforce shortages, and lengthy waiting lists [39,40]. The complexity of funding, inconsistencies between Acts, and number of parties involved in the current system are concerning, because these challenges may demotivate professionals and lead to ambiguity and frustration among care recipients and caregivers [20,40]. Such challenges have consequences for caregivers' experiences and increase concerns that they will become overburdened [46].

## Data Availability

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

## Disclosure

NWO played no role in the design, execution, analysis, and interpretation of the data, or writing of the study.

## Conflicts of Interest

The authors declare that there are no conflicts of interest regarding the publication of this article.

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