PRAGRESS

Preventing and confronting agressive behavior of older people in Long Term Care

PRAGRESS

Intellectual Output 1 – Baseline report

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Introduction

Over the next three decades the number of people older than 65 in the European Union (EU) is projected to follow an upward trend, peaking at 149.2 million inhabitants in 2050. Older peoples' relative share of the total population will also gradually increase and is projected to reach 28.5 % in 2050 (Eurostat 2019). This means that more and more people in the EU are living a longer life. However, ageing is also associated with a decline in physical, mental and social conditions. Consequences include increasing numbers of chronic diseases and frailty in the older population in the EU. Indeed, 50 % of the European population aged 50 plus years are pre-frail or frail (Manfredi et al. 2019), and the risk of dependency and requiring support from others rises with advancing age. Becoming dependent on support from others is a crucial lifetime event. In light of this, it is no surprise that research clearly indicates a high rate of anger, threats, verbal and physical aggression and even violent behaviour among older people (Zeller et al. 2012; Lindt et al. 2020). Moreover, the literature overwhelmingly suggests that aggression directed toward both formal and informal caregivers by older care recipients is under reported (Onwumere et al. 2019; Isham et al. 2017). In contrast the issue of elder abuse received has received much attention, which is exemplified by recent and current EU-funded projects, such as WeDO: Wellbeing and Dignity for Older People (2010 – 2012) and EmPreV: Empowerment of older women – Preventing violence by challenging social norms in Serbia and Austria (Franz et al. 2010).

Data on the subject of aggressive behaviour towards caregivers by older people points to a relatively high prevalence, suggesting a need for further investigation. Studies show varying prevalence rates, "ranging from 1.2 incidents of aggressive behaviour per day [to] 1 – 4 incidents per year" (Sharipova et al. 2008). Aggressive behaviour by dependents has also been identified as a significant factor contributing to the risk of burnout in formal caregivers (Simon et al. 2005). It remains unclear however, which factors contribute to aggressive behaviour and what kinds of strategies might help caregivers to prevent or reduce aggressive behaviour. Furthermore, knowledge is incomplete around the impact of aggressive behaviour on caregivers and care recipients.

The aim of this baseline study was to gain an understanding of the different parameters that shape the overall context and nurture the phenomenon of aggressive behaviour by older people towards caregivers. This baseline study represents the first intellectual output of the PRAGRESS project (Preventing and confronting aggressive behaviour of older people in Long Term Care). The overall aims of the PRAGRESS project are to develop an e-learning platform, which will be an open educational resource environment under the format of a "Massive Open Online Course" (MOOC), offering e-learning modules for both formal and informal caregivers. In addition, the platform aims to raise awareness of aggressive behaviour towards caregivers, so as both to help improve the quality of life of older people, and to facilitate empowerment of caregivers.

This baseline study serves as foundation for all further steps within the PRAGRESS project. This report first outlines the findings from a review of the literature. It then details the study design and results, and discusses these.

In order to provide clarity the PRAGRESS project distinguished between formal and informal caregivers. According to the definition of the *Encyclopaedia of Gerontology and Population Aging*, the different forms of caregiving are understood as follows:

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"*Formal care for older people usually refers to paid care services provided by a healthcare institution or individual for a person in need. Informal care refers to unpaid care provided by family, close relatives, friends, and neighbours. Both forms of caregiving involve a spectrum of tasks, but informal caregivers seldom receive enough training for these tasks. Formal caregivers are trained in the field, but the depth of their training varies."* (Li & Song 2019).

Literature review

Definition of aggressive behaviour

There is no consensus around a precise definition of aggressive behaviour (Isham et al. 2017). Though there is consensus that aggressive behaviour is a multifaceted construct (Parrot/Giancla, 2007). Baron and Richardson (1994) offered a well-accepted definition of aggressive behaviour more than 25 years ago, suggesting that aggressive behaviour is:

> *"any form of behavior [by a resident/elderly person and their closest relevant] directed toward the goal of harming or injuring another living being [formal caregiver or informal caregiver] who is motivated to avoid such treatment."* (Baron& Richardson 1994, p.7 in: Parrott/Giancola 2007, p. 283).

This definition highlights the desire of a caregiver to avoid harm. At the same time, in order to measure aggressive behaviour, many researchers distinguish between verbal and physical aggressive behaviour. This distinction has none the less been criticised because it expands rather than narrows any definition. Furthermore aggressive behaviour is difficult to define as relevant subtypes may not directly refer to a form of aggressive behaviour, but rather to related phenomena, such as anger (Parrott/Giancola 2007, p. 283 ff.). To compound matters further, 'violence behaviour' and 'aggressive behaviour' has been used interchangeably throughout much of the literature (Isham et al. 2017).

In nursing research, aggressive behaviour has also described as violent behaviour or mistreatment. Often subtypes or forms of aggressive or violence behaviour like manipulation, pouting, invading privacy, crying, verbal and physical abuse, refusing to take medication and calling the police as control maintenance techniques, being pushed, slapped, grabbed or being yelled or sworn at, are used to describe older peoples aggression towards caregivers (Ayres/Woodtli 2001, 326-334). The meta-ethnographical research by Nybakken et al. (2018) for example, offered a range of definitions of aggressive or violent behaviour that are especially used in nursing research. When looking at these different definitions of aggressive or violence behaviour, it becomes evident that they are all refer back to the well-established definition provided by Baron and Richardson in 1994.

In the definition of Isaksson et al (2009) "*the intention of doing harm to a living being*" shows similarities with the definition by Baron and Richardson (1994). However, in contrast to Baron and Richardson the full definition from Isaksson et al (2009) integrates anger as another relevant concept. Ultimately, Nybakken et al. (2018) have shown that the usage of different aspects from different definitions of aggressive or violent behaviour is quite common.

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Another definition in nursing research derived from Zeller et al. (2012): "*Aggressive behavior" is defined as an over act, involving the delivery of noxious stimuli to (but not necessarily aimed at) another organism, object or self, which is clearly not accidental. It may be verbal or physical harm or threats to another person*. This definition has obviously similarities to Baron and Richardson, but provided a far more broad definition, as the authors describe aggressive behaviour in terms of both verbal and physical aggression.

Herron/Wrathall (2018) have shown that in dementia care especially, addressing challenging behaviour is dominated by control, containment, and medication. Here, a strong medical perspective is obvious, as the focus is often more on the disease than on the person. Within such lines of thinking, medical treatment seems to be the only option presented for addressing aggressive and especially challenging behaviour (Sandvide et al. 2010, p. 158).

In summary, most qualitative studies in nursing research dealing with aggressive behaviour tend to conceptualise aggressive behaviour as subtypes of behaviour, including physical, psychological, emotional, and sexual dimensions of harm (Nybakken et al. 2018). Though as noted earlier, a precise definition defies consensus. Within the PRAGRESS consortium, the definition of aggressive behaviour by Baron and Richardson was deemed to be the most suitable working definition. This definition includes any form of physical, verbal or emotional harm or injuring. Although it is well know that people with dementia have a tendency toward more aggressive behaviour, no further criteria is added to the working definition.

Prevalence of aggressive behaviour

With regard to the prevalence of aggressive behaviour by older people against their caregivers studies show varying prevalence rates, "*ranging from 1.2 incidents of aggressive behavior per day [to] 1 – 4 incidents per year*" (Sharipova et al. 2008). In 2005, the European *Nurses Early Exit Study* (NEXT study) showed that one in four formal caregivers in long-term care had experienced aggressive behaviour by care recipients, resulting in increased emotional stress for the nurses. Aggressive behaviour by care recipients has also been identified as a crucial factor contributing to the risk of burnout in formal caregivers (Simon, et al. 2005). In light of such concerns, there have been efforts to develop specific prevention and de-escalation training programmes for caregivers within the European Union (Hirschberg et al. 2009). Nevertheless, the prevalence of aggressive behaviour has remained high. According to Zeller et al. (2012), 80% of formal caregivers of Swiss nursing homes reported experiencing regular aggressive behaviour against them during a 12 months period. In a similar fashion, Hirschberg et al. (2009) reported that 94% of formal caregivers in clinical eldercare facilities and 90 % of formal caregivers in ambulant care services had experienced verbal aggression by care recipients in the previous 12 months. More recently, Schablon et al. (2018) found in a large quantitative study with 1984 participants an alarming prevalence of aggression. Only 20.5 % of the health and social care staff had not experienced some form of violence behaviour in the previous 12 months. Staff in geriatric care were the most likely affected by daily physical or verbal attacks (Schablon et al. 2018).

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Strategies and emotions

In spite of the high prevalence in both formal and informal care, recent data shows that research continues to focus almost exclusive on the experiences of formal caregivers working in long-term care. Only a few research studies have explored the experiences of informal caregivers. As formal and informal caregivers are two different groups, detailing the distinction is of use. Formal caregivers are considered to be those who have at least one year of nursing training, while informal caregivers, who are mostly relatives, friends or neighbours do not generally have any professional (nursing) training (Li & Song 2019; Franz et al. 2010). Formal and informal caregivers and their relationships to their care recipients also differ significantly. Unsurprisingly therefore, responses and strategies to aggressive behaviour differ between formal and informal caregivers.

Since the 1990s, studies have shown that formal caregivers most often tolerate aggressive behaviour from patients. At the same time, formal caregivers frequently experience emotions such as fear, which can interfere with their ability to respond to aggressive behaviour appropriately. Formal caregivers largely describe experiences of aggressive behaviour in terms of emotional stress, as they experience negative feelings such as powerlessness, fear, and specifically fear of failure, and sadness (Hirschberg et al. 2009). In order to cope with these situations, they are using calming techniques, response strategies, repressive or sanctioning interventions, for example, isolation of care recipients, holding with force, ignoring care recipients' need for help or administering medications to reduce aggressive behaviour (Campbell et al. 2014; Sandvide et al. 2010)

Formal caregivers are specifically educated to manage aggressive behaviour. Nevertheless, despite training, they can often be unable to apply their knowledge in practice. Schablon et al. (2018) have shown that the frequency of exposure to verbal abuse leads to a high stress level for formal caregivers. While participation on de-escalation training had no effect on their stress level. The results suggest that the effectiveness of some of the recommended approaches might be insufficient to prevent and to deal with aggressive behaviour.

Only a few research reports concentrate on strategies used by informal caregivers to respond to aggressive behaviour. Pickering et al (2015) for example, have shown that daughters can react to aggressive behaviour by their mother with counter-aggression. For daughters, as informal caregivers, initially at least, getting revenge can feel liberating. At the same time, counter-aggression also often leads to feelings of neglect of the care recipient and to social isolation (Pickering et al. 2015).

In summary, two aspects seem particularly significant with regard to aggressive behaviour in older care recipients. First, aggressive behaviour by care recipients against both formal and informal caregivers seems likely more common than reported, often because it is widely tolerated and so there is a culture of silence. Unsurprisingly therefore, experiences of violence are often described in the literature as influencing emotional burden (Hirschberg et al. 2009; Nybakken et al. 2018; Rosenberg & Herron 2019). In addition, studies observe that formal caregivers often show deficits in applying efficient aggression management strategies. Caregivers often react to aggressive behaviour with feelings of fear, sadness or failure, which arguably increase the risk of burnout (Sandvide et al. 2010; Simon et al. 2005). In the case of informal caregivers, coping strategies can have a destructive effect on the relationship

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between the informal caregiver and care recipient (Pickering et al. 2015; Isham et al. 2017). Second, care recipients equally suffer from the consequences of their aggressive behaviour, regardless of whether they act against formal or informal caregivers. Furthermore, unhealthy coping strategies used by formal and informal caregivers can result in a risk of brutalization of relationships, further reducing the dignity of the care recipient (Martinez-Zaragoza et al. 2020; Nordtug et al. 2021, Stall et al. 2019).

Aim of the study

The purpose of the baseline study was to explore the phenomenon of aggressive behaviour of older people towards their caregivers, both formal and informal, across a number of different nations. This study serves to inform the different parameters that shape the overall context and that can nurture the phenomenon of aggressive behaviour of older people towards caregivers.

Study design

Sampling

Each partner of the PRAGRESS project participated in the baseline study and recruited participants in their respective country. 21 caregivers from five European countries (Finland, Germany, Greece, Italy, and Ireland) were included.

As a convenience sample should cover a wide range of experience, formal and informal caregiver are included. Basic demographic details were collected from participants, including gender, experience and cultural background/ethnicity (see Table 1 for explanation).

Table 1 Sampling criteria

Demographic characteristics	
Gender	Caring, regardless whether it is a formal or informal, is still highly dominated by women. In Germany for example, more than 80 % working in the aged care sector are women (Statista 2021). Similarly in Ireland, 80% of social care workers are female (Power & D'Arcy, 2018). This proportion in Gender is reflected in the sample.
Experience	Experience focusses mainly on the years of professional work experience. Benner associated in her study, years of work experiences with the gaining of expertise (Benner 2000). The criterion of experience is also documented for informal caregivers, as such experience reflects Benner's conceptualisation (2000).
Cultural background/ethnicity	Nursing and care staff shortages in many European countries have led to significant proportions of non-native staff. Such staff have diverse cultural backgrounds and due to differences in cultural background and education, they possible have a different

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	perspective on aggressive behaviour (Sandvide et al. 2010; Walsh & O'Shea, 2009).

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Data collection

Data collection utilised semi-structured interviews and due to the ongoing Covid-19 pandemic the majority of interviews were by phone or online (e.g. Zoom). These semi-structured interviews included a short questionnaire to collect demographic data from participants and an interview guide depending upon the type of carer – formal/informal (see Appendix B, Appendix D and Appendix E). The duration of the interviews varied between half an hour and one hour.

Key aspects in the interview focused on:

- Participants subjective definition of aggressive behaviour
- Causes and triggers of aggressive behaviour
- Prevalence of aggressive behaviour
- Management and strategies
- Feelings and emotions when aggressive behaviour occurs
- Support
- Knowledge regarding aggressive behaviour

The semi-structured interview guides were based on the literature review (see Appendix A, Table 3: literature review). The interviews were audio recorded and each partner transcribed the interview in the language of their respective country. Each partner then documented the main results in a summary (written in English).

Ethical consideration

All participants were provided with a written information sheet outlining the aims and procedures of the study in advance and all gave written consent for the interview and its recording (Appendix C). Participants were informed that the recorded information would be kept confidential and would be destroyed once the interviews had been transcribed. In order to ensure participants anonymity a coding system was applied to interview recordings and transcripts. In addition, participants were assured of their right to withdraw at any point without giving a reason and without being prejudiced in any way (Streubert & Carpenter 2011).

Data analysis

Data analysis employed content analysis and the project team developed categories and coding rules for data analysis before data collection took place (see Appendix F, Table 4 Coding system). The process of data analysis was a deductive multi-stage process (see figure 1).

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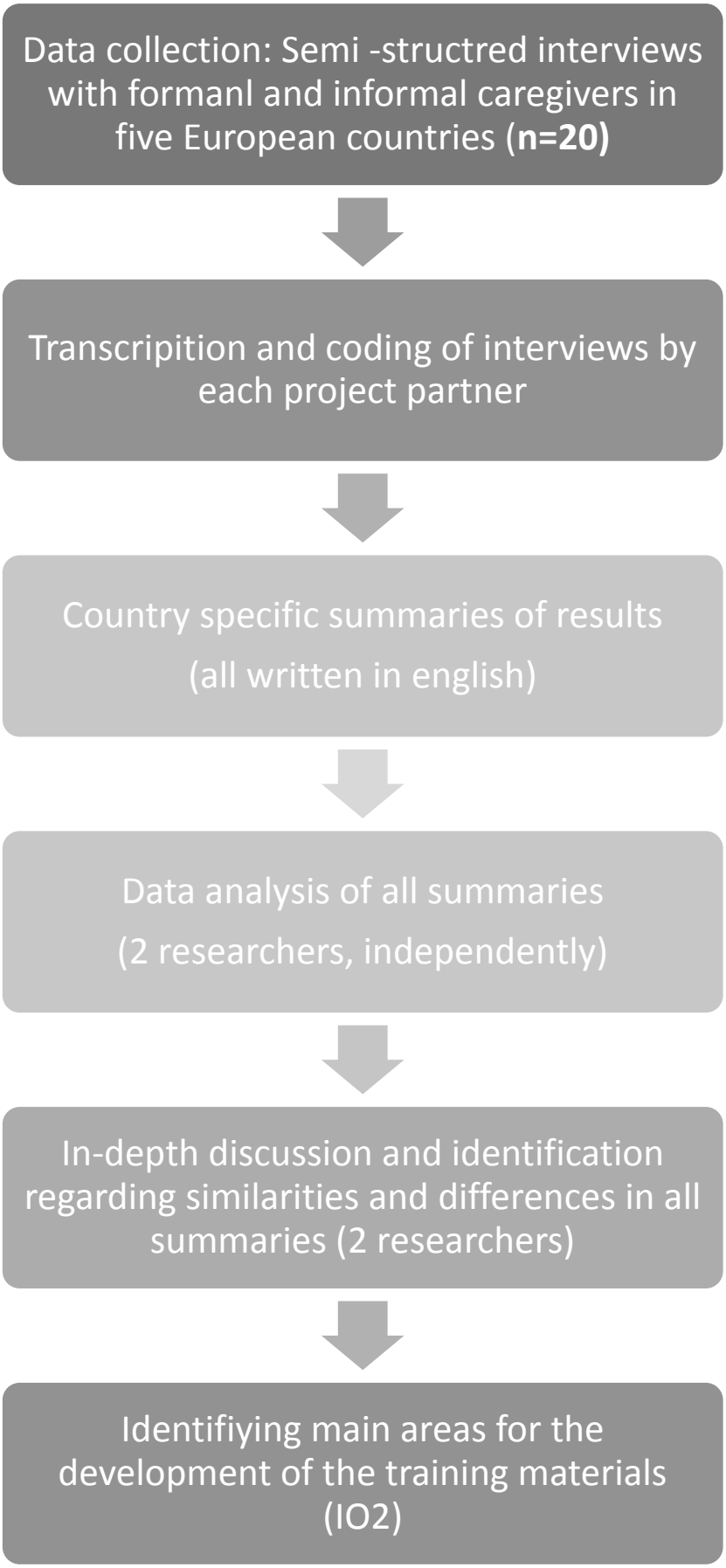

Figure 1 Multi-stage process data collection and data analysis

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Results

In total 11 formal caregivers participated and 10 informal caregivers (n=20). The age of formal caregivers varied between 18 and 60 years and informal caregivers were between 31 and 61 years of age. All formal caregivers who participated in this baseline study worked in a full-time position. Years of caring experience covered a broad spectrum for formal and informal caregivers (see Table 2).

Years of Experience	Formal Caregiver	Informal Caregiver
0-5 years' experience	2	4
6-10 years' experience	4	3
11-19 years' experience	4	1
More than 20 years' experience		1
	1 Participant missing data (Years of Experience)	

Table 2 Years of experience of formal and informal caregiver

With only one exception all participants, regardless of whether they were formal or informal caregivers, were born, grew up and currently lived in the country in which the interview took place. One participant was originally from Nigeria and thus would have been born and grew up in different country to where he/she now lived and worked.

National Background (cultural background)

- Formal Caregiver: Finnish, Greek, German, Irish, Italian, Nigerian
- Informal Caregiver: Finnish, Germany, Greek, Italian

The main results of the semi-structured interviews are presented by category and include analysis of the responses of both formal and informal caregivers.

Subjective definition of aggressive behaviour by participants

Most of the participants showed a tendency initially to report largely physical aggressiveness (e.g. swinging arms, kicking, slapping, punching, grabbing, squeezing caregiver's hand, throwing objects, pushing people and objects away, stiffening in resistance to being maneuvered, and auto aggressive behaviour, for example biting oneself). As aggressive behaviour was probed further the participants also described verbal aggressiveness, such as swearing, insulting or shouting, offensive language, yelling and care recipients' tendency to get angry when contradicted. Less often named by participants were forms of emotional aggressiveness, with only a few participants describing emotional pressure as aggressive behaviour.

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These understandings of aggressive behaviour are consistent with the findings in the literature (see Nybakken et al. 2018). Nonetheless, it evident that formal and informal caregivers tended to explain aggressive behaviour predominately in terms of physical and verbal aggressiveness. Only by further exploration did caregivers include emotional aggressiveness.

Causes and triggers for aggressive behaviour by older care recipients

One of the most reported causes, mentioned by all participants, was a diagnosis of dementia. This is very much in keeping with the literature, which highlights that persons with dementia commonly demonstrate a higher incidence of aggressive behaviour (Bartholomeyczik et al. 2006). Some formal caregivers described dementia as an underlying condition that shaped the situation and dementia specific units were singled out as likely to be sites of more aggressive incidents and behaviours.

In addition, participants noted difficult experiences from childhood and a complex personality as possible underlying causes for aggressive behaviour. Formal caregivers reported negative feelings like frustration by care recipients due to not being listened or not having their wishes respected as causes and triggers for aggressive behaviour.

Participants also reported side effects of medication, as well as the volume of medications an older person was receiving as triggers that might contribute to aggressive behaviour. Furthermore, the intimacy of the relationship was often mentioned as a potentially trigger for aggressive behaviour. Formal caregiver especially interpreted aggressive behaviour as a reaction, resulting from a concern by the care recipient of being forgotten or not listened too. Among formal carers, high rates of staff turnover was also suggested as another trigger. This resulted in an absence of continuity of caregivers, which tended to foster aggressive outbursts. Similar effects were described for task-orientated approaches to care, for example rushing through care, sudden movements by the caregiver or the wishes and preferences of the care recipient going unrecognised or responded too.

Prevalence

Only three formal caregiver suggested that aggressive behaviour (physical, emotional-psychical and verbal aggressiveness) occurred once or twice a week. Other formal caregivers perceived the prevalence as low but highlighted the importance of this topic. Some formal caregivers reported low numbers of aggressive behaviour incidents, but over the course of the interview mentioned that the incidence might be far higher, but often went unreported due to the normalisation of aggressive behaviour as part of the job, particularly where dementia was present.

The reported prevalence amongst informal caregivers was highly important, since there is a dearth of research in this area (see Pickering et al. 2015). Informal caregivers reported (verbal) aggressiveness on a daily basis and informal caregiver reacted similarly to formal caregivers, perceiving aggressive behaviour as part of daily living, adopting the view that *“you get used to it”* (SE1145).

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Management of aggressive behaviour and support

Formal caregivers differentiated responses to incidents of aggressive behaviour in terms of "management in the situation" and "afterwards, later". During a situation in which aggressive behaviour occurred management of the situation was described as positively influenced if the caregiver was calm, patient, responded by speaking softly, was empathic, or when the caregiver left the situation or distracted the older person or discussed with them the aggressive incident.

Informal caregivers regularly reported the same strategies as formal caregivers. However, they mentioned that they sometimes raised their voice, started a conflict or even sent their partner to the hospital. Where formal caregivers only reported positive strategies, informal caregivers also reported negative and destructive strategies that they had used.

In relation to 'after' the event, formal caregivers reported discussions in team meetings, coaching, supervision or adjustment of the care plan as responses to aggressive behaviour. Formal caregivers further reported that an important source of support were their colleagues. Some formal caregivers highlighted the professional aspect of caring as important to coping, which they understood as: *"Don't take it personally, that is very very important."* (ENFE89).

Many of the formal caregivers reported that the healthcare system and the long hours they worked served to foster situations for aggressive behaviour to occur. These impressions repeatedly come through in the interviews with formal caregivers.

The most important supports highlighted by informal caregivers came from their family members and close friends. In addition, assistance could also come from support groups or local services. However, it was obvious in a number of cases that a significant obstacle for many informal caregivers was to first realise that they needed support.

Feelings and Emotion

Emotions were often mixed and altered over time. All participants, formal and informal, described feelings of anxiety, fear, surprise, shock, upset, helplessness, powerlessness, disappointment, and self-blame for doing something wrong, as well as feelings of concern for both the older person and caregiver, and for the safety of other staff in the case of formal caregivers.

A formal caregiver with more than ten years' experience described his*her emotions as:

> "*feeling very sad and being incredible wounded […] and I had no idea first how to deal with this […] took me two or three days also emotional to get back to my normal self.*" (ENFE89).

Comparable feelings were described by another formal caregiver who noted:

> *"Thoughts, like is this normal, this is not what I want to do! Is this part of my job, do I have to tolerate this? You get used to aggressive behavior – it is frightening!" (SU0884).*

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When reflecting on their emotions formal caregivers showed a strong tendency to question, if they have to tolerate aggressive behaviour. One formal caregiver commented that, *"Nurses in general have no knowledge how to draw boundaries and show their limits"* (SCFE91).

All informal caregivers mentioned feelings of sadness and not knowing how to react at first, some felt scared, especially when faced with physical aggressiveness. One informal caregiver described always being alert, due to previous incidents of aggressive behaviour and suggest that it is a feeling that accompanies them always.

While the initial feelings of both formal and informal caregivers to aggressive incidents were very similar, over time informal caregiver often replaced their initial emotions with empathy and understanding.

Knowledge

In terms of knowledge that might be useful when confronted with aggressive behaviour, most of the formal caregivers acknowledged a potential to better understand dementia and become more person-centered.

Informal caregivers similarly valued education and greater understanding around underlying illnesses and conditions, though not just specifically around dementia. They also articulated the benefits of support through opportunities for the exchange of personal experiences.

Both, informal and formal caregivers recommended training, particularly strategies to reduce aggressiveness and de-escalation strategies for when an incident did occur.

Culture

In some of the interviews with formal caregivers' organizational-care culture was highlighted as problematic. This was observed across formal care participants regardless of the different countries these participants lived and worked in. Characteristics of this culture were a strong focus on routine and task orientated care. Within this culture formal caregivers respected the care receiver as an individual, were generally supportive, helpful and cared in a person-centered way. However, there were obvious challenges to the provision of a high quality of care due to the prevalence of routine and task oriented approaches, which were often shaped by high demands such as insufficient time and/or a lack of staffing and resources. As such, on the one hand, formal caregivers aimed to provided tailored individual care. On the other hand, they often struggled to achieve this against a backdrop of high workload/demands that fostered routine and task-orientated approaches, which became embedded into the organisational culture or general culture of care.

Discussion

The purpose of this baseline study was to explore the phenomena of aggressive behaviour of older people towards their caregivers. It became obvious that aggressive behaviour by older care recipients against formal or informal caregivers is a multilayered phenomenon. When asked to define their personal definitions of aggressive behaviour, all participants reported

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physical and verbal aggressiveness initially. Only some participants extended their definition to include emotional aggression. These definitions are consistent with the established definitions of aggressive behaviour, such as those by Parrott/Giancola (2006).

The prevalence of aggressive behaviour by care recipients in general if often reported in the literature as likely to be high. For example, a previous meta-analysis analysed no less than 71 reports regarding aggressive behaviour by patients in clinical settings (Papadopoulos et al. 2012). While the findings of Isaiah et al. (2019) showed that age, marital status and years of work experience were factors that predict the frequency of aggressive behaviour by patients toward psychiatric nurses. Age and experience were inclusion criteria for the sample in this baseline study. However, the results did not suggest any correlation between age or experience and a frequency of aggressive behaviour.

In a similar fashion, studies have regularly highlighted underreporting of violent incidents against nursing staff (Ferns, 2006) and in healthcare settings in general (Gillespie et al, 2016). Most worryingly perhaps, this appears to be an embedded feature of care work, which shows few, if any, signs of diminishing. The findings of this baseline study suggest that this may in large part be due to normalisation, particularly among formal caregivers, of aggressive behaviour as part of the job. Pouwels et al. (2019) indicated that prevalence rates were high in patients with traumatic brain injury, with verbal aggression (median 33.0%) occurring much more often than physical aggression (median 11.5%). Although within this baseline study, a focus on dementia and aggressive behaviour was not a specific topic for investigation, most formal caregivers reported spontaneously that aggressive behaviour was common in cases of dementia. In addition, formal caregives showed a tendency within the interviews to explain and often excuse aggressive behaviour as a feature of dementia. This is consistent with Jackson and Mallory (2009) who stated that, "*Aggressive behavior is, unfortunately, a common consequence of dementia*." While this is the case, caution also needs to be exercised and such statements should not be considered blanket statements, since a person in an early or even middle stage of dementia is potentially able to actively participate or be part of decisions for a certain time interval. In addition, a default position of viewing aggressive incidents solely as a consequence of dementia can only lead to ignoring that there may be other causes/triggers, resulting in a less person-centred focus.

Herron and Wrathall (2018) for example, highlighted in their study a deficit in research regarding an exploration of the networks of social and physical environments in which person-centred care takes place. Although person-centred care is the dominant paradigm today, and not just in dementia care, little literature has focused on the involvement of care recipients in discussing a situation in which aggressive behaviour has occurred.

In contrast, Schablon et al. (2018) highlighted that institutions offered supervision (58.5%), guidelines on how to react (27.3%), and follow-up care discussions (26.4%) as responses. These supports are reflected in the participant responses in this baseline study. In a related fashion, Gillis et al. (2019) have highlighted the relationship between the manner in which care is delivered and aggressive behaviour. More often than not, psychosocial interventions and care are delivered by a single caregiver and not by a multi-disciplinary team, which can result in unfulfilled needs for the care recipient. In addition, the effectiveness of some recommended approaches to prevent and manage aggressive behaviour, especially de-escalation training has been called into question due to insufficient evidence. A systematic review by

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Heckenmann et al. (2015) and a study by Baig et al. (2018) both highlighted that de-escalation training leads to higher confidence levels and coping skills in formal caregivers. However, the frequency of patients' aggressiveness did not change (Heckenmann et al. 2015, Baig et al. 2018). De-escalation training might therefore at best help to treat some of the symptoms rather than the underlying cause.

When considering the feelings and emotions felt by caregivers, such as anxiety or feelings of helplessness, which all participants mentioned, there are evident difficulties in managing and dealing with aggressive behaviour among both formal and informal caregivers. Formal caregivers can benefit from the positive effects of receiving support from management and peer support (Stutter et al. 2017). This is reflected in the comments of formal caregivers in this study. Informal caregivers also highlighted the benefits of peer support and sharing personal experiences with other informal caregivers.

Both formal and informal caregivers discussed changes in emotions over time and differences between in the situation and post-situation emotions. Here, formal caregivers tended to respond in the situation with positive strategies, while informal caregivers sometimes resorted to maleficent strategies, no doubt fueled by charged and negative emotions. This provides a valuable insight into informal caregiver strategies, which only a few other publications report (see Pickering et al. 2015). Informal caregivers also tended to alter their emotional response to empathy and increased understanding over time.

A cross national concern highlighted by formal caregivers was a culture of task-orientation in care, which was often linked to high demands and a lack of continuity of carer. This is in line with other research that has highlighted that such situations result in less than person-centred approaches that can trigger aggressive behaviour by care recipients (Holst & Skär 2017; Fazio et al. 2018). At the same time, Stutte et al. (2017) questioned the possible solution of "more staff less aggressive behaviour" with findings that staffing levels showed no significant effect on aggressive behaviour in their study. As such, the solution is not simply a case of more is better. Indeed, the NEXT study highlighted that one in four formal caregivers in long-term care experienced aggressive behaviour by care recipients and suffered from emotional stress. Furthermore, this study documented emotional stress as one of the main reason that nurses in Germany left the job (Simon et al. 2005). Clearly, there are economic follow-up costs resulting from an early exit by formal caregivers, as well as follow-up costs for the healthcare system due to emotional caregiver burden, along with potential conditions, such depression, burnout or abuse. Thus, there is a need to be aware of the complexity and interacting of different dynamics around aggressive behaviour by care recipients.

Limitations

The sample for this baseline study included 20 formal and informal caregivers in five European countries. While the sample size is adequate for a baseline study in qualitative research, the limitations are obvious in the case of exploring selected aspects in detail. The need for varied communication methods for data collection, e.g. telephone-interview, video-interview and face-to-face, is also a factor that potentially impacts the comparability of the interviews. Especially as data collection by telephone-interview or video interviews is likely to differ in comparison to in-field research provided by face-to-face interviews, particular in terms of data richness.

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Although recent evidence suggests that virtual forms of data collection alter the relationship while still generating in-depth exchanges (Tremblay et al. 2021). Nonetheless, it remains challenging for qualitative research during a pandemic to realise its full potential.

Furthermore, only one project partner is a native English speaker and all other partners translated for the summary and researcher discussion. This is a potential source of errors due to missing translation, as intentions or dialectic manner can often only be found in the original language (Polit & Beck 2004).

Conclusion

The results of this baseline study are in line with other research and this study once again highlights a continued underreporting of aggressive behaviour by care recipients against formal and informal caregivers (Gillespie et al. 2016). Underreporting is itself complex. In the case of formal caregivers there is clearly a perception that aggressive behaviour is simply part of the job, particularly in dementia care. Among both formal and informal caregivers aggressive behaviour may also be perceived as a failing in some way of their care, complicating emotional responses with feelings of embarrassment, shame or guilt. These factors no doubt contribute to underreporting and highlight the need for ongoing and further research.

All participants reported negative feelings of anxiety, fear, helplessness and sadness when experiencing aggressive behaviour. Formal caregivers most often received support in terms of supervision, coaching or talking with colleagues, informal caregivers mostly received support through family members and close friends. At the same time, given the high prevalence rate of aggressive behaviour, it seems that support may help the care giver deal with aggressive behaviour, but it does little to prevent or reduce it occurring. This is in line with research that has not found any evidence for the effectiveness of de-escalation and prevention training in reducing the frequency of aggressiveness (Heckenmann et al. 2015; Baig et al. 2018). The results of this baseline study along with other research suggest that formal and informal caregivers are likely to be suffering emotionally and often have few resources to draw upon to prevent or successfully deal and cope with aggressive behaviour by care recipients (Simon et al. 2005). On the grounds of economic costs alone, improving measures that enhance the quality of life of older people and/or strengthen resilience and empowerment in caregivers therefore seem appropriate. In light of such considerations, the PRAGRESS project is developing an e-learning platform (MOOC) that is based on the results of the presented baseline study and reflects the complexity of aggressive behaviour as a multilayered phenomenon.

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Appendix A Literature review for Semi-structured interview

Area of interest	People with Dementia (Prevalence of aggressive behavior against Caregivers around 60%)	Informal Caregivers	Formal Caregivers
Causes/explanation for aggressive behavior	**Trigger for aggressive behavior are well known** Individual, interpersonal, local environmental, macro-scale and temporal dynamics that influence the actions of people with dementia and carers' capacities to work with them (Herron/Wrathall 2018). **Combination of pain & cognitive impairment** Several studies found that residents with a cognitive impairment show more aggressive behavior (Talerico et al. 2002, Voyer et al. 2005, Testad et al. 2007). Ohet al. (2004) compared aggressive with nonaggressive residents and found that aggressive residents had significantly more cognitive impairment and more pain and had stayed longer in the nursing home than nonaggressive residents." (Zeller et al. 2012) **Environment** Crowding and noise level as triggers are reported for units with no special care unit for dementia (Morgan et al. 2008, p. 334-346).	**Causes are unknown** **Lack of research with this group** "We suggest that developing a clearer and more sophisticated understanding of what harmful behavior toward family caregivers looks like, feels like, and means is the cornerstone of any future work in developing knowledge and increasing understanding. Exploring how it differs in a range of social and cultural contexts is also necessary." (Isham et al. (2019), p. 635) **Violence as ongoing life pattern / lifelong relationship with violent** Prevalence: 18% of elders used physical violence against the informal caregiver 34% of elders were verbally abusive against informal caregiver (Steinmetz 1988). She observed that these behaviors appeared to be a continuation of early and	**Need to explore further the causes of aggressive behavior and** **inconsistent Definition** Parrott/Giancola recommend interview strategies that assess acts that cause harm to others (Parrott/Giancola 2007, p. 293). Different measurement tools to assess the cause of harm/violence/aggressive behavior (Parrott/Giancola 2007; Isham et al. 2017). Even some of the causes or triggers are nowadays have been identified; there is still a lack of understanding why elderly persons are aggressive against their (formal/informal) caregiver. **Part of the job** Becoming accustomed to violence and accepting violent behavior (not only from elderly person with dementia) as normal, a part of the job (Sandive et al. 2010; Morgan et al. 2008, 334-346). **Political actions/ view of the society** Sandvide et al. (2010) notes that political movements, especially in Sweden, had a strong impact on the discussion of violent behavior in elderly care. Political discussions have highlighted that every person have the right of their own "normality" (e.g. dressing, smelling, sleeping patterns). The downside has become the legitimization of violent behavior in elderly care.

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		ongoing life patterns within the family (Steinmetz in Ayres/Woodtli 2001; Isham et al. 2017). Cause of aggressive behavior from elderly against their informal caregiver still today explained as an ongoing life pattern.	**Staffing level** Rushing care due to inadequate staffing levels (Morgan et al. 2008, p. 344-346). Higher staffing level haven't shown any significance in aggressive behavior in the study by Stutter et al. (2017). **Organizational failure** Lack of support by the organization, when aggressive behavior occurs (Morgan et al. 2008, p. 344-346). **Lack of recovery** prolonged exposure to an aggressive work environment with little room for recovery (Kind et al. 2018, p. 11-16). **Young age & lack of self-care abilities (not a cause but a trigger)** It is a challenging time to transits from student life into professional life. Newcomers lack ability to self-care and are quite unprotected against burnout (Merluzzi et al., 2011; Schmid et al., 2017; Steinlin et al., 2017).

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Forms of aggressive behavior	See research and literature Challenging behavior people with dementia	**Control techniques used by caregivers were also used by the older people themselves** they used manipulation, pouting, invading privacy, crying, verbal and physical abuse, refusing to take medication and calling the police as control maintenance techniques (Ayres/Woodtli 2001). **Violence happens isolated** Violence occurred within the homes, when no other people are around (Onwumere et al. 2018)	Consensus that the **most commonly encountered violence is verbal abuse** (Patient/resident to nurse)– to be found in a sufficient number of research, regarding formal caregivers (nurse) (e.g. Carlsson et al. 2004)
Feeling/ emotional level	**Knowledge is power** Knowing about Triggers for aggressive behavior assists the ability to care and provide high quality of care. Person-centered strategies preferred (Holst/Skär 2017).	**Fear** Informal Caregiver fear their own safety (Onwumere et al. 2018)	**Low self-esteem** Nurses and Nursing Aids blame themselves, when receiving violent or aggressive behavior (Morgan et al. 2008, p. 344-346). **Lack of protective factors** **Lack of self-caring** ➔ **High risk for burnout** To find in young age (Newcomers) but also nurses, who have prolonged exposure to an aggressive work environment with little room for recovery (Kind et al. 2018, p. 11-16).

Table 3 Literature review for Semi-structured Interview Guide, Appendix A

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APPENDIX B Participant Information

Participant information PRAGRESS semi-structured interview

Interview information

Date of interview	
Name of interviewer	
Code	
• 1st two letters of surname • Month of birth (two numbers) • last two numbers of birth year	e.g. Miss Miller, date of birth: 1st of March 1955 Code: "MI0355"

Personal information

Age group	18-30yrs 31-45yrs 46-60yrs 61+ yrs
Sex:	M F Intersex
Nationality/ ethnicity (cultural background)	

Professional information

Type of caregiver	Formal CG Informal CG
How long have you been working as caregiver?	
Employment status	Part time / full time etc. pp.
Nationality/ ethnicity (cultural background)	

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APPENDIX B Participant Information

Participant information

Dear Sir or Madam,

welcome to our project "Preventing and confronting aggressive behavior of elderly in Long Term Care". We would like to thank you for your interest and participation in our project.

The goal of the project is to develop an e-learning platform to raise awareness to aggressive behavior in older care, and to offer professional training for caregivers in the field. Therefore, **XXXXXX** interviews formal and informal caregivers in long-term care about their personal experience with aggressive behavior from residents. The interview will last approximately 1.5 hrs., and will be audio-taped.

All data will be collected anonymously, which means that personal data cannot be traced. All data and personal communication collected in the context of this study are confidential. Interview data will be stored and managed by the individual project partners. For further information, please contact your interviewer/ project management.

Participation in the study is voluntary and only possible with your consent. You may revoke your consent at any time without stating any reasons, and without incurring any disadvantages. Please sign the enclosed declaration of consent if you have fully understood the nature and course of this study, you agree to participate and are aware of your rights as participant in this study.

If you have any questions, please feel free to contact **XXXXXXXXXXXXX**

For detailed information, please visit the project website at www.pragress.eu.

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Appendix C Written Consent

Declaration of Consent

I have been informed in writing about the project and its purposes. I have read and understood all the information provided regarding this study. Possible questions were answered fully by the interviewer/ project management.
I agree with the handling of the data as described in the participant information above.
I am aware that my name will not appear in connection with the data collected in the interview, but will be anonymized via a coding system. I am aware that the data retrieved in the course of this study will be stored for at least 10 years, and that I am entitled to revoke my consent to the usage and/or preservation of this data without incurring any disadvantages.

I am aware that

- the interview is conducted for research purposes only
- I am free to withdraw from the project at any time and without giving reasons, and to withdraw any unprocessed data I have provided
- the interview will be audio-taped and recordings will be stored at Duale Hochschule Baden-Württemberg Stuttgart (Baden-Wuerttemberg State University at Stuttgart)
- all data and recordings pertaining to this study will be destroyed after 10 years
- my identity will be anonymized in all publications arising from this study
- I will be provided with a copy of the data collected in the interview

I agree that the data I provide will be used for the research purposes of the above-mentioned project.

I have received a copy of the participant information and the declaration of consent, respectively.

Place, Date & Signature of the Participant Name of Participant in block letters
In case of questions or comments, please contact:

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Appendix D Interview guide formal caregiver

Interview guideline

Semi structured interview for **formal** caregiver

1	a. Today we want to talk about aggressive behavior. Could you tell us what aggressive behavior is to you (e. g. describe a specific situation or potential behavior of care recipients that you would describe as aggressive behavior)? b. Can you think of other situations / behavior when you think of aggressive behavior?	
2	a. Have you personally experienced aggressive behavior from residents? b. How common, do you think, is aggressive behavior in residents? c. In your experience, what would you say is the most common form of aggressive behavior - physical, verbal, or emotional aggressive behavior?	
3	What do you think motivates aggressive behavior in residents?	
4	**Question 4 only ask, if they have <u>personally experienced</u> aggressive behavior.** a. Going back to the situation when you experienced aggressive behavior, can you recall what you did? Was there something that may have triggered the situation? b. Do you know how your colleague(s) reacted when you told them about this specific situation? c. Have you spoken to anyone else about this experience? (e.g. your partner, friends)	
	If Formal Caregiver **has <u>personally experienced</u>** aggressive behavior …	If Formal Caregiver **has not personally experienced** aggressive behavor …
5	Can you remember what it felt like to be in this situation?	Can you remember what your colleague said about how he/she felt in this situation?
6	Can you think of any sort of support that would have been helpful to you in this situation or in similar ones?	Can you think of any sort of support that you think would been helpful, when experience aggressive behavior? Can you think of any sort of help or support your colleague would have appreciated in this situation? Did she/he mention anything in this regard?
7	Thank you	

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Appendix E Interview guide informal caregiver

Interview guideline

Semi structured interview for **informal** caregiver

1	a. Today we want to talk about aggressive behavior. Could you tell us what aggressive behavior is to you (e. g. describe a specific situation or potential behavior of care recipients that you would describe as aggressive behavior)? b. Can you think of other situations / behavior when you think of aggressive behavior?	
2	a. Have you personally experienced aggressive behavior from your partner / father / mother-in-law….? b. How common, do you think, is aggressive behavior in residents? c. In your experience, what would you say is the most common form of aggressive behavior - physical, verbal, or emotional aggressive behavior?	
3	What do you think motivates aggressive behavior in your XXXX (e.g., partner / friend / mother…)	
4	**Question 4 only ask, if they have <u>personally experienced</u> aggressive behavior.** a. Going back to the situation when you experienced aggressive behavior, can you recall what you did? Was there something that may have triggered the situation? b. Have you spoken to anyone else about this experience?	
	If Informal Caregiver **has <u>personally experienced</u>** aggressive behavior …	If Informal Caregiver **has not personally experienced** aggressive behavior …
5	Can you remember what it felt like to be in this situation?	
6	Can you think of any sort of support that would have been helpful to you in this situation or in similar ones?	Can you think of any sort of support that you think would been helpful, when experience aggressive behavior?
7	Thank you	

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Appendix F Data analysis Coding system

Categories	Description of category	Rules for coding	Theoretical background
Definition aggressive behavior	Subjective Definition by interview participants. Attributs by interview participants regarding aggressive behavior. Do they describe different form of aggressive behavior (e.g. emotional, physical)	All forms of definition or attributes described by participants	PRAGRESS Definition of aggressive behavior is: For the PRAGRESS consortium, the well-accepted definition of aggressive behavior by Baron & Richardson is used: *Aggressive behavior is understood as "any form of behavior [by a resident/ elderly person and their closest relevant] directed toward the goal of harming or injuring another living being [formal caregiver or informal caregiver] who is motivated to avoid such treatment."* (Baron& Richardson 1994, p.7 in: Parrott/Giancola 2007, p. 283). In this definition, the resident/older person and his/her closest relative is harming or injuring another living being. Harming and injuring includes any form of physical, verbal or emotional harm or injuring. The group of residents/older persons and close relatives is not an exclusive group. Although we know that people with dementia have shown a tendency to more aggressive behavior, no further criteria will be added to the group of older persons and their closest relatives other than that they did receive care in informal or formal care settings. Literature have shown that there is no overall definition of aggressive behavior, also the terms victim and abuse found in the literature. Therefore an under as well as over reporting is documented (Isham et al. 2019; Cooper et al. 2008).

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Explanation of causes and “triggers” of aggressive behavior	Causes and triggers for aggressive behavior.	All forms of explanations given by participants to explain causes or triggers • Misinterpretation of situation • Environment (Herron/Wrathall, 2018) • Illness • Pain • Dementia • Feeling ashamed Triggers might be • Irritation of routine Newly staff	Medical Socialization Formal caregivers could have knowledge but mainly explain aggressive behavior due to their medical socialization as a normal reaction due to illness. “Normal reaction” Informal caregivers have less/no knowledge and explain aggressive behavior as “normal” reaction due to ageing. Also most informal caregivers are women, still socialized “to be nice” and don’t speak up. **Relationship** Most assaults occur during personal care (Bridges-Parlet, Knopman, &Thompson, 1994; Crocker & Cummings, 1995) **Past history** There is some evidence to suggest that people who were violent and abusive in their earlier life—or who had a poor relationship with their family member in the past—are more likely to continue to experience violence and abusive behavior in later life (Isham et al. 2019)

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Prevalence of aggressive behavior	Suggestion about prevalence of aggressive behavior, prevalence of forms of aggressive behavior (e.g. emotional, physical,…)	Prevalence of aggressive behavior (e.g. happens every day, once a month, never) Prevalence of forms of aggressive behavior (e.g. only physical aggressiveness happens, Or more physical aggressive behavior, seldom emotional aggressiveness).	**Prevalence** Residents with dementia show more challenging and aggressive behavior against their caregivers. Patient with first episode psychosis show aggressive behavior against their informal caregivers. Patient with serious mental illness shown 10-40% aggressive behavior.
Management of aggressive behavior	All forms of management, concrete how do they handle the situation	Description of management, dealing of situations when aggressive behavior occurs. e.g.: - Use of special communication style - use of medication - contact a doctor - use validation - leave the situation - become also aggressive - cry - Report (like incident reporting forms)	It is still a taboo for informal and formal caregivers to report aggressive behavior received by residents.

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Feelings & emotions	All forms of feelings and emotions	All forms of feelings and emotions being said or can be identified by interpretation of the interview e.g.: - helpless in the situation - feeling worthless - sad - fear (Onwumere et al. 2019) - high impact on own (professional) self esteem - non emotional reaction, get used to it, resignation (Sandvide et al. 2010)	
Support	All forms of support	Support on all levels, e.g.: • Description off emotional support, like talked to the team • Use supervision • Holidays • Changing the ward/shift	It is also a theme of workplace safety. Resilience Self-esteem and self care

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		• Own Experience (to become less agitated by aggressive behavior) • Support due to workplace safety (e.g. Culture of Zero tolerance)	
Knowledge	Advice and Ideas about knowledge one should have	Advice and Ideas about knowledge one should have e.g. Special knowledge about dementia care, like validation.	Family Caregivers (informal caregivers) have less knowledge than formal caregivers (Ayres/Woodtli 2001). Nursing Aids due to the organization (hierarchy) are less involved with their knowledge about the resident in the decision making process (RN makes the decision).
Free category	Coding rule: If you have any text which doesn't fit in the category above but seems very important to you. Code it and label it in a new suitable category.		

Table 4 Coding system

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