


A responsibility that never rests – the life situation of a family caregiver to an older person

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Background: When the ageing population increases, the burden and responsibility of close family members will likely increase. Those closely related who assume a great responsibility can be significantly affected in health, well-being and daily life.

Aim: This study aims to describe the life situation when family caregivers are imposed responsibility for an older person with complex care needs in their own home.

Methods: In this Swedish qualitative study, ten family caregivers were strategically selected in order to achieve variations in the life situation. A reflective lifeworld research design based on phenomenological philosophy was used throughout the data collection with the life-world interviews and the analytic process.

Findings: In terms of extensive responsibility, the life situation is complex and involves emotions that are difficult to manage. In essence, a paradoxical life situation is described

which is experienced as both *voluntarily and nonchosen at the same time*. *The responsibility never rests*. The essential meaning is further illustrated with three constituents: *loss of freedom, contradictory feelings* and *affected relationships*.

Conclusion: A life situation with extensive responsibility for an older family member interferes with the whole life situation with an impact on health and relationships with other people. The findings are crucial for professional caregivers in order to capture the nature of family support in a way that enables a meaningful life for both the family caregiver and the older person being cared for. Knowledge of this will give professional caregivers an increased awareness of the life situation of family caregivers and provide a better understanding of the support they are longing for, and, in some countries, such as Sweden, also are entitled to by law.

Keywords: caring science, closely related, family caregiving, home care, informal care, lived experience, older people, phenomenology, reflective lifeworld research.

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Background

In Western countries, the increase in the number of older people, as well as structural and organisational changes in society, has led to greater numbers of older people who need care in their own homes. This study highlights the situation of family caregivers in Sweden providing home care for an older person. The care described is based on Swedish care model legislation and the conditions under which home care is publicly financed and available to all citizens in need. Older people can apply

for and receive social and medical interventions after undergoing an individual evaluation. Since the turn of the millennium, every fourth elderly home facility in Sweden has been closed. This places increased responsibility for extensive support and assistance on older people, on the people they live with, and on professional caregivers. The need for care increases with age, and older people are affected by multiple illnesses; this increases their need for complex care at home. Thus, it is more difficult for them to manage on their own. There is a need for more advanced at home health care, which may also affect the entire family and those closely related, hereinafter referred to as family caregivers. While professional care has decreased, family care has increased (1). Sweden is considered to be a welfare state where everyone in need should have equal access to formal support. Even so, Sweden follows the Scandinavian trend

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in which organisational changes in healthcare delivery assume that families will increase their participation in caring for loved ones (2). Thus, there are implicit expectations that family members will increase their caring responsibilities. Bookman and Harrington (3) described the authorities' expectations when families to step in and assume some of the duties as a 'shadow workforce'.

The Social Services Act legislated in the 1980s is the foundation of home care for older people in the community who need care and support, but family caregiving duties are not regulated. However, there is a statutory requirement that family caregivers have the right to be supported in accordance with the Social Services Act (4). A family caregiver is 'a person who cares for relatives who are long-term ill, elderly or disabled' (5). Help is required at least once a week, and one-third of those people require more than 10 hours of assistance every week (6). In Sweden, family care has become more common than professional care (7), and family caregivers are the major providers of care for older people (8). Approximately 1.3 million Swedes care for, assist or support a close relative. This means that closer to one in every five adults takes an extended responsibility. In Sweden, another change that complicates the situation for families is the introduction of the 2018 law regulating cooperation when a patient is discharged from inpatient care (9). The law reduces the number of days from five weekdays to three calendar days for municipality to take fully treated patients home from hospital. The change in legislation aims to ensure that the transition from hospital care to home care is safe and secure, but it places high demands on municipalities and county councils to cooperate to facilitate these matters.

In Sweden, it is very unusual for family members from different generations to live together. Yet, family is highly valued and ties are often strong as they frequently take great responsibility for the care of their loved ones (8). A family caregiver can be a spouse, a child or a close friend performing different tasks and caring actions that significantly affect their health, well-being and daily life. When a family caregiver is a spouse, it is common, in Sweden, that they are also older, ill and/or frail. Both men and women provide support for family members, but from a practical standpoint, in different ways. Women often help with personal care, while men help by transporting and shopping for groceries (10). Problems may arise for people who volunteer to take on a major responsibility, for example women tend to use vacation and unpaid leave to care for their parents (10) or may need to retire early (6). Family caregivers often balance the expectations placed on them with the willingness to actually be able to work (2).

In many other countries, similar situations arise for people that take responsibility for family care. Becoming a family caregiver is described as an endless responsibility

(11, 12) implying that it imposes limitations on the caregiver's daily life (13, 14). A Spanish study showed that extensive responsibility for an older person entails an increased risk of negative consequences, such as anxiety and stress due to the subjective burden (15). Despite the impact on health, many Nordic family caregivers value the possibility of being involved and think that caregiving is worthwhile (16, 17). While being a family caregiver in Nordic countries is a free choice, it is often limited by duty as well as by social and economic resources. Many family caregivers find caregiving to be too demanding (16).

Thus, while Swedish family caregiving is an important issue, affecting older persons and their closely related, it is also the responsibility of the entire society, as the 2001 Social Services Act (4) gives family caregivers the statutory right to be supported by municipality. While many studies have described the consequences of family caregivers' efforts (14, 16, 18), few studies (17, 19, 20) have focused on the impact on the caregivers' own life situation. Therefore, there is a need for more research focusing on the lived experiences of what it means on a personal level to take great responsibility for caring for an older person with complex care needs.

Aim

This study aims to describe the life situation when family caregivers are imposed responsibility for an older person with complex care needs in their own home.

Ethical considerations

Approval and permission to undertake the study were obtained from the Ethics Committee of the Medical Faculty at the University of Gothenburg (Dnr 484-16). Written permission was given by the head of the department in the municipality. The study was conducted in accordance with the Declaration of Helsinki (21); thus, the participants received written and verbal information about the aim of the study, that participation was voluntary, and that they could withdraw anytime without any personal consequences. All material was treated as confidential. Because family caregivers are in an exposed situation, participation could bring up feelings that can be difficult to talk about. This was considered before, during and after the interview. The nurse in charge was informed about the study, and the participants could turn to him/her if they needed further support.

Approach and method

The research process was guided by a reflective lifeworld approach with a phenomenological stance (22). Phenomenology as philosophy and epistemology was

introduced by Edmund Husserl in the early 20th century. In a phenomenological sense, a phenomenon is understood as something that is lived (experienced) by a person. Thus, a phenomenon is something that manifests itself and appears in human consciousness as the meaning of something (22). In order to understand another person's lifeworld, one's own experiences of similar issues must be kept at bay; this entails questioning one's experiences and one's pre-understanding of the phenomenon in focus. In order to do that, a bridling attitude (22) is used in phenomenological research meaning that the researcher maintains an open mind. Openness is to be open and sensitive to discover new ways, in order to see the phenomena studied. This means trying to restrain one's own pre-understanding in order for the phenomenon to reveal itself in all of its variations. Therefore, in the present study, the epistemological assumption is family caregivers' perceptions of their own life situation in which they assume extensive responsibility for an older person. Hence, by the concept, lifeworld, Husserl meant the entire world of 'things' that matter to us personally. Consequently, the lifeworld is unique to each of us and it consists of all that what is taken for granted in everyday life.

In order to describe the phenomenon, which is the life situation with extensive responsibility for an older person cared for in his/her own home, Dahlberg's phenomenological approach for analysing data was chosen (22). The method involves analysing the meaning and reporting findings as an essential meaning of the phenomenon with its associated constituents.

Participants and data collection

The data were collected in a municipality in south-western Sweden during 2017. Ten family caregivers with different caring relationships to an older person were interviewed (Table 1). The participants were strategically selected in order to achieve as much variation in the data

as possible. The following inclusion criteria were used the following: the participants had to have extensive responsibility as a caregiver on a regular basis, their caregiving should continuously and frequently occur several times a week, and they should also be active in caring for the older person to the extent that their own daily life is affected. Finally, the participating family caregivers provide caregiving even though professionals from municipal social services can do so.

The family caregivers were initially asked whether they would like to participate in the study by the home care nurse who was responsible for the older person. The family caregiver was informed briefly about the purpose of the study and asked whether they agreed to be contacted by the researcher. All of the family caregivers agreed to be contacted and to participate in the study. The interviews were performed in a place chosen by the family caregiver; the interviews were recorded and transcribed. One initial question was asked to stimulate reflection about the research phenomenon; '*How do you experience caring for an older person?*' In order to stimulate reflections, follow-up questions were asked to deepen the understanding.

Analysis

The phenomenological analysis is characterised by the search for meaning in lived experiences through a movement between the whole (interviews) and its parts (meanings in data) in the research data set, thereby formulating a new whole (the essential meaning). In this method, the analytic process is characterised by an open, flexible and bridled attitude so the participants' responses are not determined in advance (22). The analysis started with a reading through the transcribed interviews several times to obtain a sense of the data as a whole. Thereafter, the analysis of parts began by identifying the meaning units associated with different aspects of the phenomenon. Similarities and differences in the meaning

Table 1 Participant characteristics

<i>Participant</i>	<i>Gender</i>	<i>Year of birth</i>	<i>Relationship</i>	<i>Living with the older person</i>	<i>Year of birth of the older person being cared for</i>
1	Female	1935	Wife	Yes	1929
2	Male	1939	Husband	Yes	1930
3	Female	1941	Wife	Yes	1940
4	Female	1936	Wife	Yes	1934
5	Male	1936	Husband	Yes	1936
6	Female	1959	Daughter	No	1934
7	Female	1951	Daughter	No	1925
8	Female	1949	Wife	Yes	1927
9	Female	1938	Partner	Partially	1935
10	Female	1934	Wife	Yes	1932

units were identified and compared. Meaning units with similar meaning formed clusters, which are concentrated abstractions of meanings. Based on how they relate to each other through patterns of meaning, this allowed an essential meaning to emerge by moving between the whole, the parts, and the new whole, the essence. The essential meaning of the phenomenon is further illustrated with the description of three constituents, the meanings that constitute the actual essence. The constituents give 'the contextual flavour' to the essence and exemplified with quotes from the original source (23).

Findings

Essence

The essence is a paradox, with the meaning that family caregiving for an older person is at the same time both nonchosen and voluntary. This paradox is always present since the contradictory life situation affects almost all dimensions in everyday life. Imposed responsibility for an older person can be understood as an unspoken requirement from others and from society. Such feelings can be overwhelming and never ending. Yet, in this respect, it is also paradoxically, because it can become an opportunity to participate and to be close to a loved one.

The responsibility implies a never resting continuum; it affects life to the extent that it no longer can be lived as it was before. The responsibility is lonely in its need for constant preparedness, which cannot be put aside. Thus, responsibility primarily supersedes everything else that is important making it difficult to control your own life. To this comes a sadness over changed relationships with the older person and others in life. The life situation is difficult to influence and change and requires more than actively trying to allocate dedicated time for recovery. The changed life situation creates new feelings that must be handled that affect well-being raising existential concerns.

Constituents

Three constituents describe the phenomenon further: *loss of freedom, contradictory feelings* and *affected relationships*.

Loss of freedom

For a family caregiver, life has become stressful and challenging; it changes from being self-chosen and autonomous to being complicated and limiting. This type of existence may be difficult to imagine before becoming a family caregiver. The situation requires family caregivers to be present most of the time, which changes life in such a way that it cannot be lived as it was before. The situation affects life physically and mentally, raising

thoughts about the present and the future. Anxiety over what will happen next is often present as the fear of an even worse situation unfolding or the death of the person being cared for. The caregiver must be prepared for anything to happen at any time, which, in turn, creates the stress of never being able to rest from responsibility.

Then I became a caregiver after three years... And it was instantly! I got completely stuck! // Yes, something pulled me in... Closed me in. Now you have to... Who else will do it?

The lack of freedom feels heavy; life is described as being a struggle in which the feeling of wanting to give up emerges. Sometimes, this makes a person feel helpless and uncertain about what to do with the lonely sense of responsibility. Nonetheless, the family caregiver has no alternatives other than fighting and not giving up.

Yes, it feels very heavy... It is a very heavy responsibility. But, I'm not the one who gives up in the first place, I'm not. I'm trying. But, of course, it's very heavy'.

Existence can be perceived as being lonely when there is no one else to take the initiative and share responsibility. One aspect that alleviates the feeling of being stuck is when the responsibility is shared with others, such as professional caregivers or another family caregiver. Shared responsibility means that the caregivers' life situation becomes easier to handle and loneliness is not as noticeable. This also creates an opportunity to rest momentarily and to feel freer.

We were out there drinking coffee. I felt like a princess. I thought it was so wonderful that day. Then you feel like a completely different person... when you get away from home.

Contradictory feelings

The life situation brings up emotions, some of which are difficult to handle, resembling an emotional roller coaster. While irritation and frustration, which sometimes unconsciously and uncontrollably affects the people around you, are difficult to feel, you are inevitable.

Yes, but I'm not always as nice as I should be // It is such a frustration. And then I get frustrated at her [the older person]. I should not be but I am. Annoyed and frustrated.

The life situation also provokes feelings of guilt, for example in the moment when one's time is prioritised for a while. It may be necessary to switch between different roles in order to protect oneself to feel good. This means family caregivers actively need to force themselves to rest from responsibility and engage in other activities. There is a need to cope by getting out of the house for short moments, going to the store, or applying for temporary help from professional caregivers from the municipality. These moments bring new power and strength and can be seen as rewarding.

These times can also be riddled with guilt and feeling bad because time away from responsibility can be enjoyable. Despite understanding the need for recovery time, it is difficult to describe it when doing so results in a shameful feeling and not properly prioritised.

My friends said: Take off, go away! Stay away for a few days. But, it is not that easy. // Then I would feel even worse. I would feel guilty.

Prioritising self-care can be perceived as a necessity. The emotional roller coaster affects the family caregiver's well-being and has mental and physical consequences. The life situation means pondering what causes concern and uncertainty, which is difficult to handle on one's own.

But then I can admit that I get upset and then... I had a high blood pressure for years which I must remind myself about sometimes.

The life situation creates a kind of emotional duality, and it can be difficult to manage and contributes to internal struggle. Family caregivers can simultaneously feel gratitude at being able to take responsibility and care for someone else while also feeling that they do not want, or are morally unable, to give up. There is also a duality in wanting to be free from their responsibility, but simultaneously not wanting to be the person that does not help their closest one's. There is a stated willingness to do what one can to help out, which in theory makes the situation self-chosen regardless of knowing that it is a voluntary responsibility that can be refused and ignored. However, turning ones back on someone is not perceived as being a choice. All those contradictory struggles require family caregivers to maintain a constant balancing act between wanting to fight and wanting to give up.

I feel tied because it is hard to leave him for longer without knowing that someone is looking after him
// At the same time, I feel ambivalent because I want to help him. I want to give support in every way.

Affected relationships

A family caregiver's relationship with the older person, as well as others, changes when the caring responsibility takes precedence in daily life. The space for time, energy and patience is limited; there is no longer equal space for the private relationship. Love and other emotions are still there when a family caregiver needs to worry about how to manage the present everyday life and what will happen in the future.

But I feel that I am the one pushing... lifts her over the jar so she does not fall into the syrup and being practical one // ... It does not feel like... the mom-daughter relationship has disappeared a bit.

Simultaneously, as responsibility unfolds, the situation changes in line with the decision-making and resources

provided by the municipality. This impacts the family caregiver's personal life, and it affects the relationship with the older person as time and energy are used for practicalities and struggles. Being the one who is constantly present entails that there is no room for the relationship to stay the way it was before.

Yes, it's sad; but, in some way, I had to put it away.

// So, our old relationship, it is gone.

Secondarily, the changed life situation also affects relationships with others when being a family caregiver becomes the priority. Relationships are sometimes affected to the point that a caregiver can no longer be the person he/she used to be. Fatigue affects the caregivers' daily life. The energy to nurture other relationships is no longer as available as before, not because the caregiver does not want to but because it is difficult to cope. This can bring up feelings of not being enough, no matter how hard one tries. However, caregivers still need support from and cooperation with others.

Before... I had my colleagues when I worked but now they are gone. Everyone disappears... you lose so many. Friends who pass away. And then those who are a little younger, they find it difficult when a conversation is not possible in the same way because of the disease. Life changes.

Strengths and limitations

'Going to the things they themselves' was one of Husserl's basic assumptions. In the present study, a phenomenological stance was chosen according to Dahlberg, Dahlberg and Nyström (22) with a phenomenon in focus. The strength of this study is that individual interviews are performed in order to gain in-depth statements, raising voices of family caregivers. The findings give nuances of family caregivers lived experiences with openness to the phenomenon. Therefore, it feels reasonable to believe that through a phenomenon-oriented attitude, it has been possible to contribute to more knowledge in the area. On the other hand, qualitative research often raises concerns about trustworthiness such as the number of participants. The question of variation is more important than the question of sample size (22). Sample size cannot be decided in advance as the focus is to find variations of a given phenomenon which means that data in this study were collected as long as the phenomenon varied. One limitation could be that the collection of data is done in a limited geographical area. On the other hand, the participants vary according to age, gender, relationship and place of residence, in order to increase the conditions for a varied description of the phenomenon. The findings also seem to be similar with international studies which make the findings transferable in a larger context.

All family caregivers were interviewed in a place chosen by themselves in order to stimulate to an open

atmosphere, mostly carried out in the family caregiver's home. In some situations, interviews were interrupted as professional caregivers worked at home simultaneously and needed help from the family caregiver. Some interviews were also interrupted when the older person was in need of help. This shows the complexity of being a family caregiver further. Interruptions may have led to losing context and valuable data may have been lost. However, the researcher role was made conscious through the process, in order to capture and stimulate reflection in the best way possible without affecting openness.

The interviews were rich in meaning but there were sometimes difficulties in telling. Perhaps feelings of guilt can emerge that affected the ability to talk about difficulties that come with being a family caregiver. It was therefore important to create a trustworthy relationship where it felt safe to share lived experiences.

Reflections on the findings

The findings of this study show that family caregiving for an older person means contradictory feelings to that extent that the whole life situation becomes paradoxical. The responsibility never rests, and this changes the life situation in an overall way. The situation changes life; freedom is lost because the responsibility is always present, even when the older person also receives assistance from professional caregivers. Often, the older person is dependent upon professional caregivers and family members, but in different ways. A good and reasonable balance is needed between the professional's occupational role and how much of the professional duties can be carried out by family caregivers. This balance can be viewed as inadequate. We can also assume that when family caregivers are too occupied with care, many other dimensions of everyday life are lost at the expense of an effort that society should be able to address. Despite the solid efforts of home care services, family's lives are affected to such an extent that a caregiver's life must be put on hold; this is consistent with the findings reported in previous studies (13, 24). In the international literature, the caregiving situation of close family members is described as something that is completely absorbing (24). It influences a person's whole existence, and according to Rodger, O'Neill and Nugent (25), it creates a burden that is not actively chosen by the family caregiver. Instead, the caregiving situation is something an individual slips into without reflecting on the demands or consequences (26). It can also be assumed that responsibility can be difficult to interrupt and balance because it could be difficult to set limits when someone else's well-being is prioritised.

The present study's findings indicate that family caregivers who take great responsibility often feel alone,

partly because it is difficult to receive understanding or support from professional caregivers. With the support of previous studies, showing that older persons can have up to 25 different in-home professional caregivers visiting each week (27), one could also assume that it can be difficult for a family caregiver to know where to turn to or how to create valuable, cooperative relationships with professionals. Previous studies conducted in the United States and Ireland (3, 25) strengthen the importance of professionals to support family caregivers. Although Swedish legislation stipulates that the healthcare system must provide support for family caregivers, that support is often lacking or unclear. Family caregivers feel invisible when the law is not sufficiently clear regarding support offered to unpaid family caregivers (14, 20). Family caregivers perceive their role as important but they need to be acknowledged by professionals (28). Earlier studies in Sweden have also reported on family caregivers' need for professional caregivers to acknowledge their practical efforts and to affirm the choices made (20, 28, 29). When professional caregivers take over, it also creates free time for family caregivers for relax and recharge (17). Similar findings are indicated by the present study, and therefore, family caregivers must be given sufficient time for relief in order to provide everyday support. This is especially true for caregiving spouses, who usually assume the most responsibility, living with the older person and engage in their daily life. The great responsibility that rests on family caregivers needs to be relieved from time to time, which is a matter that must be addressed at a higher organisational level of professional care. The legislation from 2018 regulating discharge time from hospital (9) is an example of how individuals can be adversely affected. The original idea was to enable older persons to return home from the hospital more quickly; however, because municipalities already find it difficult to swiftly respond to care needs, one can assume that this responsibility will be placed on family caregivers. It is important to remember that every family is influenced by its culture with traditional norms, as well as personal concerns. Commonly, relatives repeat the same pattern of care and the same sense of responsibility demonstrated by their own parents and previous generations. A previous study on lifelong caring responsibilities showed that the life situation for family caregivers becomes easier if one learns to accept, adapt and be flexible (30).

The present study demonstrates how the life situation of family caregivers evokes contradictory feelings, as the responsibility is perceived as being both voluntary and enforced. These contradictory feelings can lead to increased uncertainty and insufficient self-confidence as being burdened with contradictory feelings can be exhausting. These findings are confirmed by the findings reported in previous research; informal care is seen as both a free choice and as a duty (31) as well as a

meaningful task (28). Family members also provide informal care because they have experienced shortcomings in professional care services; thus, they feel obliged to step in and help out (28). It is also noted that well-functioning home care is a prerequisite enabling family caregivers to continue to perceive caring as voluntary (32). This indicates that there is a good opportunity to create quality home care by increasing the interactions between professional caregivers and family caregivers. However, in Sweden, this may be challenging since professional care is constantly decreasing and the number of people in the population aged 80 and over receiving professional care decreased from 62% to 37% between 1980 and 2012 (1). In parallel with the reduction in professional elderly care, family caregiving has increased.

The efforts of family caregivers influence all dimensions of their existence. This requires them to strike a constant balance between their will and their ability. This can be understood as an existential challenge, wanting to do good and being able to do well. In line with the present study's findings, previous research also emphasised that a relative's willingness to help and care is great (6). Parts of life must be sacrificed; there is neither time nor energy to continue to live the way one did in the past. The voluntary aspect of a responsibility that never rests can be further understood from the perspective of the philosopher Lögstrup. Lögstrup (33) describes moral cohabitation and how humans relate to other humans living in an interdependence that is inevitable. He describes this interdependence as 'a silent obligation'. By this he means that, as human beings, we have 'another person's life in our hands', meaning we cannot close our eyes to another's needs. That responsibility is existential in all of us; caring and loving are essential to one's existence. Those human fundamentals can be found motivating in helping others (33). Still, there seems to be a limit in how much responsibility another person can assume. Especially when a family caregiver is old and frail and the responsibility has a great impact on the own life situation. Therefore, support for family caregivers is very important; the focus should be on them not forgetting themselves when prioritising the well-being of others.

The study's findings reveal that changes occur in the relationships between caregivers and the older person when focusing on caring activities. This might also affect the caregiver's identity, when not being able to work or to participate in social activities. This is previously discussed from other points of view when a caregiver's life slowly disappears as the older person becomes 'someone else' and personality changes due to illness. Changes in a caregiver's life situation and relationship to the older person are described as a grieving process in which the lost fellowship and the absence of physical and emotional closeness are

mourned (20). This loss is related to the transition from being a spouse, child or a friend to becoming a caregiver and can occur suddenly or evolve slowly (34). Thus, it is difficult for a family caregiver to prepare for all the consequences that are implied with such extensive responsibility. The issues relating to a family caregiver's responsibility need to be highlighted early and addressed throughout the process of providing home care to older people.

Conclusion

This study demonstrates to which extent the life situation of family caregivers is affected when caring for an older person. The findings shed light on the price that family caregivers often pay with impacts on well-being and relationships with other people. It is of crucial importance to fully understand the support those caregivers are longing for and, in some countries, such as Sweden, also are entitled to by law. However, even if the Swedish legislation highlights and emphasises family caregiver's rights to support, their life situation is affected in a way that requires sensitivity and individual adaptation. This puts high demands on the professional caregivers when providing care that include family caregivers. This must be done with a reflected attitude where family caregivers are/become a given part of the older person's everyday life and being acknowledged for all efforts provided.

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Conflict of interest

The authors declare no conflict of interest.

Author contribution

AJ, MN, ADE and IR designed the study. AJ collected the data. AJ, MN, ADE, IR and MEB analysed the data. AJ, ADE, IR, MN, MEB prepared the manuscript.

Ethical approval

Approval and permission to undertake the study were obtained from the Ethics Committee of the Medical Faculty at the University of Gothenburg (Dnr 484-16).

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