

This is a self-archived version of an original article. This version may differ from the original in pagination and typographic details.

Author(s): Van Aerschot, Lina; Kadi, Selma; Rodrigues, Ricardo; Hrast, Maša Filipovič; Hlebec, Valentina; Aaltonen, Mari

Title: Community-dwelling older adults and their informal carers call for more attention to psychosocial needs : Interview study on unmet care needs in three European countries

Year: 2022

Version: Published version

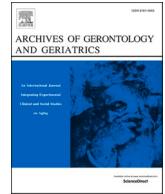
Copyright: © 2022 the Authors

Rights: CC BY 4.0

Rights url: <https://creativecommons.org/licenses/by/4.0/>

Please cite the original version:

Van Aerschot, L., Kadi, S., Rodrigues, R., Hrast, M. F., Hlebec, V., & Aaltonen, M. (2022). Community-dwelling older adults and their informal carers call for more attention to psychosocial needs : Interview study on unmet care needs in three European countries. *Archives of Gerontology and Geriatrics*, 101, Article 104672. <https://doi.org/10.1016/j.archger.2022.104672>



Community-dwelling older adults and their informal carers call for more attention to psychosocial needs – Interview study on unmet care needs in three European countries

Lina Van Aerschot^{a,*}, Selma Kadi^b, Ricardo Rodrigues^{b,e}, Maša Filipović Hrast^c,
Valentina Hlebec^c, Mari Aaltonen^d

^a Department of Social Sciences and Philosophy, University of Jyväskylä, PO Box 35, FI-40014, Finland

^b European Centre for Social Welfare Policy and Research, Berggasse 17, Vienna 1090, Austria

^c Faculty of Social Sciences, University of Ljubljana, Kardeljeva ploščad 5, Ljubljana 1000, Slovenia

^d Faculty of Social Sciences (SOC), Tampere University, 33014, Finland

^e ISEG Lisbon School of Economics and Management, University of Lisbon, Rua do Quelhas, n° 61200-781 Lisboa, Portugal

ARTICLE INFO

Keywords:

Unmet needs
Psychosocial needs
Informal care

ABSTRACT

Background: Unmet care needs are usually defined in terms of receiving sufficient help in instrumental activities and activities of daily living. Research on unmet needs is mostly based on quantitative data. Older persons' and informal carers' views and experiences have received less attention.

Methods: In this paper, we rely on a definition of unmet needs which includes both unmet needs due to insufficient care and those situations where informal carers experience undue strain. Using theory-driven content analysis, we examine community-dwelling older adults' and their informal carers' experiences of unmet needs: what kind of unmet needs they have, why and in which ways these needs are left unmet and what would they want to do to improve the situation. The data consists of interviews gathered in Austria, Finland and Slovenia.

Results: Results of the analysis reveal that unmet needs are largely psychosocial in nature. The predominating task-oriented care systems often do not consider these as care needs. Using methods of qualitative content analysis, we conclude that care users' unmet psychosocial needs are related to lacking a personal relationship with care workers; means to maintain or develop social contacts and pursue activities and interests; and adequate home care services or respite care. Excessive responsibilities are put on informal carers as they top up and fill in the insufficient care.

Conclusions: This study contributes to a broader understanding of unmet care needs: the relational aspects of care and the universal nature of psychosocial care needs should be addressed in care services.

1. Introduction

Unmet care needs refer to a situation in which a person is not receiving adequate care, either formal or informal (Kröger, Mathew Puthenparambil, & Van Aerschot, 2019). Unmet needs are defined as either a lack of any kind of assistance (e.g., Vlachantoni et al., 2011) or a lack of sufficient care (e.g., Laferrère & van Den Bosch, 2015; Maplethorpe, Darton & Wittenberg, 2015; Srakar, Hrast, Hlebec & Majcen, 2015) when a person has care needs. At the moment, research on unmet needs is mostly based on quantitative data, and though there are insights on the subject from qualitative research (Blake, Claire & Siganporia, 2017; Kuluski, Peckham & Ashlinder, 2018), these are generally scarcer.

The focus is usually on whether needs related to instrumental activities or activities of daily living (IADLs and ADLs) are met or not. A recent meta-analysis of research on informal care highlighted that the emphasis is mostly on the fulfilment of care tasks, 'caring for' – overlooking the vital emotional or relational aspects of 'caring about'. Older persons psychosocial needs are largely overlooked in research (Larkin, Henwood & Milne, 2018). More qualitative research is needed to get a deeper understanding of how both the older people themselves and their informal carers understand and define unmet needs. We also need broader understanding on unmet psychosocial needs.

The concept of need in care services remains a contested one, given the wide range of eligibility rules and definitions employed across

* Corresponding author.

E-mail address: lina.vanaerschot@jyu.fi (L. Van Aerschot).

<https://doi.org/10.1016/j.archger.2022.104672>

Received 24 January 2022; Received in revised form 25 February 2022; Accepted 3 March 2022

Available online 4 March 2022

0167-4943/© 2022 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

Europe (for a technical discussion of different eligibility criteria, see Brugiavini, Carrino, Orso & Pasini, 2017). In terms of delivering informal or more formal care services, it is often a problem objectively defining what is a care need and distinguish needs from wants. Basic care needs concerning food, clothing, accommodation, and hygiene are relatively easy to agree upon, but definitions of what is 'adequate' care, and how this care will be delivered varies according to the historical, cultural, and political context (Godfrey & Callaghan, 2000). One way to distinguish needs from wants is to consider whether it would harm or damage the person to leave those needs unmet (Lister, 2010).

The concept of unmet needs in gerontology was introduced over 40 years ago by Isaacs & Neville (1976). It describes the situation where older people receive insufficient care in terms of their basic needs for food, warmth, cleanliness, or security, and/or if caring for them puts undue strain on informal carers. It is interesting that this definition already takes into account the needs of not just the older person but also their informal carer who may be under a lot of strain when providing care -even if the person with care needs is also receiving care services. In many cases, informal carers may have to step in and fill the gaps by monitoring the health status, well-being, and various needs of the person in care when the quality and/or timing of services are inadequate (Kuluski et al., 2018). In addition, informal carers may attend to psychosocial needs that the service providers either choose or are forced to ignore. In light of this, we are using Isaacs and Neville's definition of unmet needs in the present study, as it includes both unmet needs due to insufficient care and those situations where informal carers experience undue strain.

1.1. Psychosocial care needs tend to remain overlooked

The way care services are funded, organized, and provided tends to promote fragmented and task-oriented (rather than person-centred) models of care (Larkin, Henwood, & Milne., 2018). As such, home care services are more likely to focus on supporting activities of daily living (ADL)¹ and covering basic health needs – often overlooking the psychosocial dimensions of care (Garms-Homolová et al., 2012, 67). Nevertheless, psychosocial needs are clearly included in the WHO International Classification of Functioning, Disability and Health Framework (Abdi, Spann & Borilovic, 2019); in fact, the framework has several categories concerned with psychosocial needs: emotional support, relationships, instrumental activities of daily living (IADL),² social services, social activities, and communication and information needs.

A qualitative study on unmet care needs in Britain (based on interviews among older adults receiving care) concludes that they rarely concern basic needs like nourishment or safety; unmet needs relate instead to loneliness and a lack of social contacts, an inability to participate in activities, or to get out of the house (Blake et al., 2017). These relational aspects challenge our understanding of a care provision system aimed primarily at individual autonomy and self-determination; they emphasise instead the socially embedded nature of human beings and care relationships. This may also explain why social support has been shown to positively affect both physical health (Everard, Lach, Fisher & Baum, 2000) and cognitive function (Yeh & Liu, 2003).

Older people's own assessments of good quality care emphasise these psychosocial dimensions too. They appreciate that carers have time for them and are more flexible compared to rushed and task-focused care. Most of all, older people appreciate feeling valued. The positive aspects that they attach to the experience of receiving care include a sense of reciprocity, respect, attentiveness, safety, security, and engaging in decisions about what is being done and how – all of which refer to the

relational dimension of care (de São José, Barros, Samitca & Teixeira, 2016). Older people also appreciate it when care workers have time to interact with them respectfully (Kajonius & Kazemi, 2016). A systematic review of 17 studies on older people's experiences of home care confirmed the importance of psychosocial support, time, trust, and caring relationships (Kwan, Rutter, Anderson & Stansfield, 2019). Reducing social isolation was seen to be as important as personal care (ibid.), and there is evidence that the family members of older people in care value similar things (Meagher, Cortis, Charlesworth & Taylor, 2019). This would confirm definitions of care which emphasise that it is not only comprised of tasks, but also has a very significant emotional component (Graham, 1983; Tronto, 1993).

1.2. Context of the study: welfare systems in Austria, Finland and Slovenia

When talking about unmet needs in general and psychosocial needs in particular, the nature, quality and accessibility of care provided in the three countries form an important contextual background that must be accounted for.

Finland is a Nordic welfare state offering needs-tested public care services which are often topped-up with informal care and also some private services. In 2018, 11 per cent of people aged over 75 (5.6% of those over 65) were receiving public home care services and around nine per cent of over-75 s lived in residential care (Official Statistics of Finland, 2019). Needs testing in Finnish public care services prioritises medical needs, including memory disorders, and physical disabilities over social or emotional needs, and public care services do not include psychosocial support. Although public care services should in theory be available and affordable for all who meet the needs-assessment criteria, informal care also plays an important role in Finland. Informal care is publicly supported when it is based on a contract between the local municipality and an informal carer.

The Austrian care system has been described as 'optional familialism'. Informal care and services are paid for and organized via a cash-for-care allowance known as *Pflegegeld* (Le Bihan, Da Roit & Sopadzhian, 2019). *Pflegegeld* is based on a needs assessment (i.e., it is universal) and can be used to either buy subsidised care services or compensate informal carers without the need for any formal arrangement. To determine eligibility or needs, ADLs and IADLs are taken into account as well as the user's cognitive functions. In 2016, approximately 42 % of those who use the cash-for-care allowance received only informal care, while 39 per cent received either care services only, or a combination of care services and informal care (BMASK, 2017). Nine per cent of 61–80-year-olds, and 57 % of those aged 81 and over claimed a cash-for-care allowance based on the number of hours of care they need (BMASKG, 2018).

In Slovenia, the system of care for older people could be labelled as 'familialism by default' or prescribed familialism (Hlebec, Srakar, & Majcen, 2016; Filipovič Hrast, Hlebec & Rakar, 2020). Most care responsibilities fall on families and so only a minority of older people receive care services. Family members have a legal obligation to financially support the welfare of those family members in need of support, including the costs of care in old age. In the past 20 years (Hlebec & Rakar, 2017), home care services have slowly been developing but, in 2018, home care was still only being offered to less than 2 per cent of the population aged 65 and older (Kovač, Orehek, Černič, Nagode, & Kobal Tomc, 2019, p. 80). The costs of social home care are partially supported by the municipality (at least 50%), but the availability and accessibility of these services is problematic, due to regional (even municipal) differences in access, waiting lists, and how the service is delivered (in some places it is only weekdays, others just over weekends and holidays, and other places only in the morning). Home care is also limited nationally to a maximum of 20 h per week. Because of these various factors which limit the use of public or private care services, most care is carried out on an informal basis by families at home.

¹ ADL include personal activities like bathing, dressing, grooming, toileting, eating.

² IADL include activities like shopping, cooking, managing medications, using the phone, doing housework and laundry, moving outside the home

Table 1
Characteristics of interviews and demographic features of the participants.

	Austria	Finland	Slovenia
Methods used to identify participants	Through organisations offering mobile care services, GPs, and local organisations such as churches and community centres, snowballing	Through NGOs: the Alzheimer Society of Finland and Carers Finland	Through organisations offering mobile care services, GPs, and local organisations such as churches and community centres, snowballing
Period of interviews	2019	2018–2019	2019
Number of interviews	48 interviews	19 interviews	104 interviews
Number of dyads and participants	24 dyads interviewed separately, 48 participants: 24 informal carers, 24 persons with care needs	14 dyads interviewed together + 5 individual interviews of spousal carers: 19 spousal carers, 14 people with care needs	52 dyads interviewed separately: 52 Older people with care needs, 52 carers
Informal carers' relationship with the Older Adults	21 adult children, 2 grandchildren, 1 son-in-law	19 spousal carers	?
Duration of interviews	20–70 min	45–74 min	20–70 min
Age, Caregivers	36–75 (mean 56)	62–87 (mean 75)	38–71
Age, Older persons	69–98 (mean 86)	65–88 (mean 76)	68–98
Gender, Caregivers	7 male/17 female	6 male/13 female	24 male/30 female
Gender, Older persons	5 male / 19 female	9 male / 5 female	8 male / 46 female
Activity/cognitive status of the Older Adults with care needs (n):			
Demanding care needs	17	8	18
Medium level of care needs	7	2	26

1.3. Aim

In this article, we examine community-dwelling older adults' and their informal carers' experiences of unmet needs: what kind of unmet needs they have, why and in which ways these needs are left unmet and what would they want to do to improve the situation. We use interview data from Austria, Finland, and Slovenia to build a grounded conceptualization of unmet needs based on individuals' own accounts. These three European countries represent different types of welfare state (Genet & Boerma, 2012), with care models that vary in the way that public and private services are combined and informal care delivered. As such, the interviewees represented in this data have thus experienced unmet care needs in a range of different national and local settings. However, the aim of this paper is not to compare the countries and the care provision, or how unmet care needs differ between the care systems of different countries. Rather, we use the qualitative data from these three countries to show the cross-cultural and, to a large extent, universal aspect of older people's care needs.

2. Materials and methods

2.1. Data collection and characteristics of the participants

The empirical data used in this study consists of interviews collected from dyads of older people with care needs and their respective carers in

2018–2019 across the three countries of Finland, Slovenia, and Austria. The interviews were semi-structured and similar themes were discussed in each, even if the Finnish dataset was initially planned and collected separately from the Austrian and Slovenian ones. The interviewees in all countries were asked how their daily life is organized, what kind of care they need and what is received, and whether the received care is adequate in terms of quality and quantity.

In Finland, 20 interviews were used in total; the interviewees were people with care needs and their respective spousal carers. The majority of participants (28) were interviewed in dyads, the rest (5) were interviewed alone – 33 people participated in total, and they came from several regions in Finland. The interviewees were recruited with the help of the Alzheimer Society of Finland and Carers Finland (a support group for informal carers). The associations asked their members if they would like to participate in the interviews, and those who were interested then contacted the researchers. The participants who were care receivers had care needs that varied according to their health – all of them had some kind of memory disorder ranging from mild to severe according to their own assessment; many also had physical disabilities or illnesses. However, everyone was in sufficiently good health to give their informed consent and participate in the discussion. The care receivers used also health and social care services to varying extents and some carers received support for informal care.

The Slovenian and Austrian data was collected in 2019 as a part of a larger international project that was investigating the experiences of care-dyads (Rodrigues, Filipovic Hrast, Kadi, Cerar, & Hlebec, 2022). These included older people receiving both formal and informal care, where their grown-up child is their main informal caregiver. Interviewees were recruited through snowballing, organisations offering mobile care services, GPs, and local organisations such as churches and community centres. In Austria, 24 older people and their main informal caregivers were interviewed. In Slovenia, semi-structured interviews were conducted with 52 community-dwelling older persons who had care needs and their carers (52 persons) who were predominantly their adult children. The older persons either lived alone or together with their spouse or adult children. Interviewees in Slovenia and Austria were chosen to get as widely representative a sample as possible in terms of the gender, living arrangements, or socioeconomic status of care users. Interviews were carried out individually at the participant's home, and they could choose to be interviewed either alone, or in the presence of the other member of the care dyad. (For information on interviews and characteristics of participants, see Table 1.)

2.2. Data analysis

The interviews from all three countries were recorded and transcribed verbatim. To ensure the privacy and confidentiality of the interviewees, all identification details have been erased when saving the transcribed data. Interviews were conducted in the national language of each country, German, Finnish and Slovenian, and each set of interviews was analysed by a pair of local researchers from that country. Theory-driven content analysis (Silvasti, 2014; Tuomi & Sarajärvi, 2009) was used to obtain as condensed and comprehensive a description as possible of the unmet needs that came to light in the interview data. The analysis was prepared with careful literature review and research team's discussion on definitions and types of unmet needs identified in previous research. Throughout the process, the analytical framework was discussed by all the researchers involved in online meetings.

In the first round of analysis, the team in each country summarised all the unmet needs they had come across in the interviews and coded the data by extracting descriptions of unmet needs and organising them thematically. In the second round, the thematic categories of unmet needs were discussed and data extracts from each country were combined. The analysis resulted in identifying three categories of unmet psychosocial needs related, first, to the *relationship with carers* which was mainly about hopes for personal relations that respond to psychosocial

needs. The second category consisted of unmet needs that were due to care receivers' *social isolation* or both care receivers and informal carers lacking social contacts and networks. Thirdly, the analysis resulted in a category of *unmet needs faced by informal carers as they become burdened* with care responsibilities and addressing the unmet psychosocial needs of the person they were caring for.

In the analysis, unmet needs are considered in relative terms (see DePalma et al. 2013; Maplethorpe, Darton, & Wittenberg 2015). This means that we do not limit the use of the term unmet need to those cases where a need is not addressed at all. Received care may be somewhat insufficient or largely insufficient or lacking completely. For example, when care is received, it might be so delayed in coming, or be of such poor quality that care needs are at least partially unmet. This can also be of concern to the carer and not just the care user: the care services might be of such poor quality or insufficient quantity that they lead to a situation in which the carer patches up the shortfalls, leading to the possibility of 'undue strain' being put on informal carers (Isaacs & Neville, 1976).

2.3. Ethical considerations

In all countries, the participants were informed that their participation was voluntary and that they had the option to cancel the interview at any point and stop their data being used for research thereafter. Participants were also given an information sheet informing them about how the data would be collected and handled. All research procedures followed the regulations for General Data Protection (European Commission 2018).

3. Results

In this section we use the country acronyms AT for Austria, FIN for Finland and SI for Slovenia. The datasets have been completely anonymized. It is marked after each data quote whether an informal carer or a person with care needs is quoted, the country code and the number of the interview.

3.1. Need for personal relationship with carer

Both the informal carers and users often discussed the way in which care workers deal with the relational aspects of care. First of all, a personal relationship with the care user and carer requires continuous interaction. In all three countries, the constantly changing staff made the development of relationships between formal carers and care users difficult to achieve. This was tiresome for both the care users and informal carers. They felt that changing personnel made things complicated, as new care workers often did not know what to do and how to do it. A personal relationship with carers also fulfilled the care user's need for social interaction, as explained by the interviewees.

It would be more comfortable for all of us if it was the same care workers that were here at the beginning and that others [new staff] would come slowly. Because they [original staff] also know how to do things faster, since they have always been the ones that normally come [to help]. If they are new, they always have to look into the folder, to see what and how things should be done – surely that complicates things for everyone?

(Informal carer, AT 51)

The last three times now, we've actually had the same person [care worker], so [finally] she knows how things are done here.

(Informal carer, FIN 18)

I saw that it means a lot [...]. She [the care user] has been so attached to those two ladies, and they used to talk about all kinds of things. Because if a new person comes every time [then this is not possible]. I ask her

sometimes "Did you ask them if they had any kids [...]?", but she replies that they do not have time [to talk]. Before, when there were the same people all the time, they could talk about this kind of thing and there was a more personal relationship.

(Informal carer, SI 23)

Constantly changing staff also had an impact on the quality of care that was provided because care users felt that the new staff would not know the kind of care they required and preferred. This was not so much to do with the tasks themselves, but with how care was actually carried out. In some cases, a lack of trust between care user and staff made it difficult for a good relationship to be established –resulting in stress and dissatisfaction for the care user.

The difference is that, at weekends, the carers who come do not know exactly [what to do]. The transition is not ok. Sometimes these people are new and get grandma angry as they do not know how to handle her. They often come early and seem in a hurry, as they always have more clients they need to see.

(Informal carer, SI 5)

The problem is that older people with care needs and their informal carers value and even prioritize psychosocial aspects of care while care services or home help plan and allocate the work according to particular concrete chores and tasks. Meeting psychosocial needs are clearly not a priority when planning care services. 'This social aspect', as one Slovenian interviewee described it, '[...] is missing, the other things are taken care of' (informal carer, SI 14). Socialising and the feeling that someone cares about the older person with care needs seemed more important to one Slovenian informal carer than instrumental tasks being efficiently carried out: 'It's not so important to me that they clean, but that they talk to her. More important is communication' (informal carer, SI 128). This carer points out that a practical task like cleaning an older persons home should have a psychosocial aspect.

3.2. Need for social activities

The interviewees discussed psychosocial needs in terms of need for social contacts, company and emotional support. They were not just referring to the need for care workers to foster a more personal relationship with the care user, but they also discussed that they had lost many of the means of social contact they previously had. The unmet need for social contact was often linked to the fact that older people needing care are more or less homebound. Both carers and care users expressed difficulties in maintaining social relationships and carrying out activities with other people and their peers – many had lost the friends they used to have.

So, I do not pop into anyone's house. I do not know anyone around here. And that makes me want to cry, actually.

(Care user, FIN 2)

I sometimes miss some neighbours, but they are gone.

(Care user, SI 5)

We used to be invited out every week or even several times a week but now we are not invited at all.

(Spousal carer, FIN 8)

If I see some of his [spouse with care needs] old friends somewhere I always talk to them, and they ask how he is doing. I always invite them to come round and visit because we are there [at home] all the time, but so far no one has come.

(Spousal carer, FIN 4)

24 h a day. 24 h a day for me. It is boring, to be like this 24 h a day. I do nothing.

(Care user, SI3)

Well, it is a bit hard at

(Care user, AT 6)

Some interviewees thought there should be a visiting service which would be something like home care but for taking care of socialising needs. Several informal carers and older people had concrete ideas on what kind of services or activities would meet their social needs. Interviewees described how they would like to be able to go for walks, attend concerts, or go on trips and sometimes they referred to the 'right person' that would be needed for this, again pointing to the importance of relationships.

If he had a visiting service, this would be great, a good hour and a half or so, because I also want him to [have social contacts]. If I talk a lot with him, one notices it clearly, he also learns new words.

(Informal carer, AT 10)

Maybe if someone would come and talk [with her] for a maximum of maybe one hour; or play a board game, so she gets distracted.

(Informal carer, SI2)

I would like it if a home helper [male or female] would [...] go for a walk with me.

(Care user, AT 26)

I could sit in a car and someone take me in a forest, or a park or whatever.

(Care user, AT 6)

Psychosocial needs were not only discussed in relation to having company or the relational aspects of care, but also as something that is vital for the overall well-being of both the care users and informal carers. The carers often felt that the psychosocial needs of the person with care needs were going unmet but also the spousal carers especially in the Finnish data mentioned their need for psychosocial support too – both the informal carers themselves and the care users recognised this. Interviewees mentioned the need for some sort of professional counselling but actually this was not so much for a therapist as such, but simply to have someone to talk to for emotional support.

I think you would need something subtle, subtle so it was not too obviously like psychological counselling, because people at that age are against this, right? But really it would be some kind of mental support, something that is prescribed but not paid for; because if they [older people] have to pay for it, they would not do it because this is the doctor or psychotherapist for the 'crazy people'. But I do believe talking is good for her [...] so she forgets about the pain, for example – in the short term at least – because she's thinking about other things.

(Informal carer, AT 50)

*I: What would be the support or service you need but you are not getting?
R: Well, this is good, that I can talk. That I have someone [to discuss things with] and a calm moment because I do not have anyone around here to talk to.*

(Spousal carer, FIN 9)

I would need someone to discuss with. I do cope as far as I'm able to keep my head.

(Spousal carer, FIN 1)

Well, one thing is the cooking, and another is care, not to mention the

nerves – the psychological side (LP06, informal carer, SL).

According to the informal carers, emotional support is important for care users, as talking about things with someone can make you, for instance, forget about your problems for a while. Likewise, as they are often doing all they can to meet the psychosocial needs of the care user, the informal carers also recognize their own need for conversation and emotional support.

3.3. Need for psychosocial care and support

Our analysis revealed that both groups consider the relational aspects of care to be an essential part of the process. Care services that are not delivered on a personal level, and which do not communicate the feeling of being cared about, are seen as poor quality and not meeting the care needs of the older person. This can lead to services not being taken up or accessed, as the interviewees see them as not good enough. This, in turn, often means that informal carers need to step in to top up or even fill the gap left by services. In these cases, informal carers take on responsibilities and burdens which may cause 'undue strain'.

Some of the Finnish or Slovenian interviewees were entitled to public services, such as home care or respite care (a public service provided on a monthly basis to give spousal carers a break from their care responsibilities), but they did not use them more than once because they felt the services did not correspond to their needs or idea of quality care. One Finnish spousal carer, for instance, was taking it upon herself to look after her husband because she felt the services did not address personal needs, and thus were useless. Home care would have been available for this spousal carer and her husband, but the care workers scheduled the visits according to a daily plan that did not seem to take into account the needs of care users: 'We would have received home care but they only come when it suits them. That's no use to me' (spousal carer, FIN 16).

Several Finnish spousal carers also explained how they had deliberately chosen not to use respite care due to the poor quality of service and lack of personal treatment. Respite care was expected to provide not just physical care, but also psychosocial support and some carers felt it was offering neither.

This ward for respite care [...], my spouse O. was there last autumn for one week because I was exhausted. I went to visit our children and he went to the ward, but it was the completely wrong place for him. [...] They had said that he'd get [physical] rehabilitation for his legs and the chance of counselling from psychiatric nurses and all [...], but when we got there [...] they were all behind locked doors so you could not get out at all [...]. There were people in such a bad condition, not at all like O. Only once did a nurse come to see about his legs and nobody took the time to give him any counselling or to talk with him. So, he was there all alone with no one for company, nothing. They promised so much and delivered nothing. So that place is out of the question for us – he refuses to go there and I will not take him there (spousal carer, FIN 1).

This spousal carer was clearly disappointed that what was promised in advance did not happen, and her husband was left uncared for both physically and mentally. For another Finnish spousal carer, respite care would have been the only way to get some time for recovery but the last experience, over a year earlier, was so poor that he did not want to do it again.

No, since then I have not used any [respite care] and I would not take her. It was a mistake [...] which I regretted, but the good thing is that I got to know what it is like. The patients just sit there and stare at the TV – nobody says anything (spousal carer, FIN 18).

The carer was shocked that the patients were so passive and no social activities or interaction were taking place. Some informal carers in the Austrian and Slovenian data provided care at home because they felt that the quality of residential care was so poor that it was seen to be life-threatening – a 'waiting room for death' where older people would give up the will to live.

If I took her to a care home, I would not be seeing her around for

much longer (informal carer, AT 21).

If [only] the institution was less impersonal, it could be so my mother would feel more at ease and looked after. I'm not taking this onto my own shoulders out of stupidity. My mother should be in residential care, but not when it's like this. To tell you the truth, I think she would not be alive anymore if she had gone there (informal carer, SI 14).

Our analysis showed that informal care filled the gaps left by public care services. Informal carers often put aside their own needs to make sure that the care user had what they needed – taking time and effort to respond to those needs even if it meant doing it at the cost of their own well-being. In this respect, there was a high care burden. The interviewees described this, for example, by “not having a private life anymore”, “not feeling free anymore” or “being trapped” because of care responsibilities.

Basically, as a relative, I have to say it's like being completely out of one's depth – particularly if it happens so suddenly, which was the case with mum; and well, I do not have a private life anymore (informal carer, AT 26).

I just do not feel free anymore. It is always a burden ticking in the back of my head – that there could be something (informal carer, AT 15).

What can I say? I am trapped. This is how it is; I can not go anywhere [...] I just stay mostly at home (informal carer, SI 18).

Sometimes, I can not find the strength for everything. What bothers me is the guilt that I do not do enough. For mum, for my husband, or for the kids. I am always haunted by guilt (informal carer, SI 55).

The interviewees here describe the burden of responsibility they feel for having to take care of their parents or relatives. It worries them all the time – a constant reminder ‘ticking’ in the background. The informal carers feel these overall responsibilities because there are no other people caring about the psychosocial well-being of their loved ones. In this case, the unmet needs are being experienced by the informal carers rather than care users.

4. Discussion

In this study we have analysed experiences of unmet needs as recounted by care users and their informal carers. Their narratives expose a dimension in care that is often overlooked – unmet psychosocial needs. How the welfare-state and care systems work in Austria, Finland and Slovenia are different, but the logic of defining and assessing care needs according to physical and cognitive disabilities or frailty is similar. The service systems focus on I/ADL needs and these are also the focus of a large part of the research literature (Laferrère & van Den Bosch, 2015; Maplethorpe et al., 2015; Srakar, Hrast, Hlebec, & Majcen, 2015; Vlachantoni et al., 2011; Kröger, Mathew Puthenparambil, & Van Aerschoot, 2019; Vlachantoni, 2019). It is possible that needs which are psychosocial in nature and therefore not directly related to the everyday activities of living are not duly recognized because they are difficult to define systematically and because of the aims of cost-efficiency of care services. Not recognising the psychosocial needs allows them to be left aside when planning care.

According to our analysis of the unmet needs that presently exist, community-dwelling older adults and their informal carers need (1) a personal relationship with care workers and a feeling of being cared about; (2) means to maintain or develop social contacts and networks and pursue activities and interests; and (3) that excessive responsibilities are not put on informal carers due to inadequate home care services or respite care.

When care users cannot develop a solid relationship of trust with care workers, the care delivered is deemed to be of poor quality. Care users and their informal carers expect psychosocial needs to be taken into account as part and parcel of care services offered (Kajonius & Kazemi, 2016; Kwan, Rutter, Anderson, & Stansfield, 2019). A constant merry-go-round of changing care workers lowers the quality of received care because there is little time to get to know each other. Care users were left with unmet needs when these relational aspects of care were

ignored. This is also referred to elsewhere in care research which stresses that care is not just about its provision, but also about the process of establishing caring relationships and the emotional work that comes with this (e.g., Larkin, Henwood, & Milne, 2018; Tronto, 1993). As reported in other studies, these caring relationships not only have an intrinsic value for care users (Rodrigues, 2020), but they also lead to a better quality of care overall, as care workers became acquainted with how users prefer to receive care.

The results of our analysis also showed that one significant unmet need was being given the means to maintain or develop social contacts and networks, and to pursue activities and interests. This applied not only to care users, but also the informal carers themselves – especially spousal carers – who were regularly suffering from social isolation and a lack of psychosocial support. This stems from the fact that older people with care needs spend a lot of time alone at home, and/or informal carers may also be forced to spend so much time with the care user that they also lose social contacts or have to restrict their social activities elsewhere (Van Aerschoot, Eskola, & Aaltonen, 2021). Both care users and informal carers might have lost friends and their social networks may have diminished or disappeared altogether. More social activities for people with care needs could be offered as part of care services so that these networks could be maintained, and perhaps new ones even developed. In this respect counselling, or at least the means to talk with someone outside the immediate domestic environment, should also be made available.

Finally, the consequences of these unmet (especially psychosocial) needs which came to be the focus of our research, are often foisted on informal carers. When psychosocial aspects of care are ignored, informal carers are obliged to fill the gaps. This can in many cases cause undue strain for informal carers who feel overwhelmed and unable to fully cope (Isaacs & Neville, 1976).

This is an exploratory study, but the unmet needs reported here were a common feature in the accounts of users and carers in the three different countries contained in our sample. Although the aim of this study was not to directly compare differences between the three countries, it is nonetheless noteworthy that similar unmet needs were found in both Austria and Finland, whose public expenditure ratios for long-term care are comparatively high, as in Slovenia where there is less public investment. One reason for this, is because commonly used definitions of ‘unmet need’ have usually ignored both psycho-social needs and the needs of informal carers.

The strength of this study was the extensive interview data from three different European countries. The data allowed us to reflect the universal nature of care needs and the importance of psycho-social needs. The unmet needs that were identified in the interviews were somewhat similar across countries, regardless of the national welfare state model, care services system, or role of informal care. Yet, interviews collected from different countries in local languages pose a challenge for the analysis as co-authors are not able to work with the entire sample, but researcher from each country analyse its own national data. The research team, however, took steps to minimize possible issues arising from this limitation, as described in the Materials and Methods section, such as developing a common analytical frame reflected against existing literature and discussing the meaning of identified categories of unmet needs.

The data used in this article was collected as part of two pre-existing research projects and sample composition differs. In the Finnish sample, all older adults with care needs have cognitive impairments and, in addition, other disabilities or limitations to varying extents. In Austria and Slovenia, the older participants with care needs had only very mild, if any, cognitive impairments but primarily other type of disabilities. In Finland, the informal carers were all spousal carers whereas in other countries they were primarily adult children. Yet, the large sample size allowed including a diverse set of older people and their carers in the analysis, also people with cognitive impairments who are frequently excluded from such research. Finally, a qualitative study always

represents the unique experiences and histories of the participants. Their specific experiences may not reflect the overall picture of unmet needs in each country.

5. Conclusions

In our dataset, the care users were all receiving informal care, so in that respect they did not have 'unmet needs' as defined by Laferrère and Van den Bosch (2015) and Srakar, Hrst, Hlebec, & Majcen (2015). By this definition, an unmet need is one that exists but for which no care is being offered. In our case, care users were receiving informal care (and in some cases also public or private care services); however, the unmet psychosocial needs of care users often translated into problems for the informal carers as well.

Acknowledging de São José et al. (2016) definition of care needs, the present study contributes to an understanding of their universal nature, and highlights their social, emotional, and relational character. Psychosocial needs have to be recognised and addressed to allow older adults to live at home for as long as possible (which is a generally accepted policy goal), and to ensure the well-being of both care users and their informal carers. In the future, care service planning should put psychosocial needs on a par with the physical. The focus should *not* be on task-oriented care alone – simply fulfilling individual tasks to ensure physical needs are met, but on a more holistic people-oriented form of care. This kind of personal care takes into account the psychosocial needs of older adults and their informal carers and allow them to have trusting relationships with *all* who deliver care to them, and to be able to maintain and develop healthy social contacts and activities also outside the care dyad and the home. This, in turn, will allow the informal carers to be able to feel that they can also trust in the support being offered by care services.

CRedit authorship contribution statement

Lina Van Aerschoot: Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – review & editing. **Selma Kadi:** Writing – review & editing. **Ricardo Rodrigues:** Conceptualization, Investigation, Resources, Writing – review & editing. **Maša Filipović Hrst:** Conceptualization, Formal analysis, Investigation, Resources, Writing – review & editing. **Valentina Hlebec:** Formal analysis, Writing – review & editing. **Mari Aaltonen:** Conceptualization, Formal analysis, Resources, Investigation, Writing – review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

The authors want to thank the research network on Unmet Needs, Care Poverty and Inequality (UNICAP)

Statements of ethical approval

In Finland, approval was received from the Ethics Committee of the Tampere Region (Decision 37/2018). In Slovenia, approval for the study was obtained from the Ethics Committee of the Faculty of Social Sciences, University of Ljubljana (2016–01/KERFDV). In Austria no ethical approval is required for this type of study. All participants signed a written consent form to participate.

Funding

Academy of Finland 312303; Slovene research agency (ARRS),

P5–0200 and J5–8235; Austrian Science Fund I3422-G29

References

- Abdi, S., Spann, A., Borilovic, J., et al. (2019). Understanding the care and support needs of older people: A scoping review and categorisation using the WHO international classification of functioning, disability and health framework. *BMC Geriatrics*, 19(1), 195.
- Blake, M. L., Claire, & Siganporia, Z. (2017). *Unmet need for care. Research report*. IPSOS Mori. Available at <https://www.ipsos.com/sites/default/files/2017-07/unmet-need-for-care-full-report.pdf>.
- BMASGK. (2018). *Österreichischer pflegevorsorgebericht 2018*. Wien: BMASGK.
- BMASK. (2017). *Österreichischer pflegevorsorgebericht 2016*. Wien: BMASK.
- Brugiavini, A., Carrino, L., Orso, C. E., & Pasini, G. (2017). *Vulnerability and long-term care in Europe*. London: Palgrave Macmillan.
- de São José, J., Barros, R., Samitca, S., & Teixeira, A. (2016). Older people's experiences and perspectives of receiving social care: A systematic review of the qualitative literature. *Health & Social Care in the Community*, 24, 1–11. <https://doi.org/10.1111/hsc.12186>
- DePalma, G., Huiping, X., Covinsky, K. E., Craig, B. A., Stallard, E., Thomas, J., et al. (2013). Hospital readmission among older adults who return home with unmet need for ADL disability. *The Gerontologist*, 53(3), 454–461. <https://doi.org/10.1093/geront/gns103>
- Everard, K. M., Lach, H. W., Fisher, E. B. M., & Baum, C. (2000). Relationship of activity and social support to the functional health of older adults. *The Journals of Gerontology: Series B* (Volume 55, Issue 4), S208–S212. <https://doi.org/10.1093/geronb/55.4.S208>, 1Pages.
- Filipović Hrst, M., Hlebec, V., & Rakar, T. (2020). Sustainable care in a familialist regime: Coping with elderly care in Slovenia. *Sustainability*, 12(20), 1–15. <https://doi.org/10.3390/su12208498>
- Garms-Homolová, V., Naiditch, M., Fagerström, C., Lamura, G., Melchiorre, G., Gulácsi, L., et al. (2012). Clients in FOCUS. In Nadine Genet, Wienke Boerma, Madelon Kroneman, Allen Hutchinson & Richard Saltman (eds.). *In Home care across Europe. Current structure and future challenges. Observatory studies series*, 27 WHO Publications https://www.euro.who.int/_data/assets/pdf_file/0008/181799/e96757.pdf
- Genet, N., & Boerma, W. (2012). Introduction and background. In Genet, N., Boerma, W., Kroneman, M., Hutchinson, A., and Saltman, R. (eds.). *Home care across Europe: Current structure and future challenges* The European Observatory on Health Systems and Policies Supports. Available at: <http://www.euro.who.int/en/publications/abstracts/homecare-across-europe-current-structure-and-future-challenges-2012>
- Godfrey, M., & Callaghan, G. (2000). *Exploring unmet need. The challenge of a user-centred response*. York, UK: Joseph Rowntree Foundation. Available at: <https://www.jrf.org.uk/report/exploring-unmet-need-challenge-user-centred-response> (accessed February 7, 2020).
- Graham, H. (1983). Caring: A labor of love. In J. Finch & D. Groves, eds., *A labor of love: Women, work and caring* (pp. 13–30) London, Boston: Routledge and Kegan Paul
- Hlebec, V., & Rakar, T. (2017). Ageing policies in Slovenia: Before and after austerity. V: TOMCZYK, Łukasz (ur.). *Selected contemporary challenges of ageing policy, (Czech-Polish-Slovak studies in andragogy and social gerontology, Part 7)* (pp. 27–51) Krakow: Uniwersytet Pedagogiczny w Krakowie
- Hlebec, V., Srakar, A., & Majcen, B. (2016). Care for the Elderly in Slovenia: A Combination of Informal and Formal Care. *Revija za socialnu politiku*, 23(2), 159–178. <https://doi.org/10.3935/rsp.v23i2.1317>
- Isaacs, B., & Neville, Y. (1976). The measurement of need in older people. *Scottish health service studies*, 34, no.
- Kajonius, P., & Kazemi, A. (2016). Structure and process quality as predictors of satisfaction with elderly care. *Health and Social Care in the Community*, 24(6), 699–707.
- Kovač, N., Orehek, Š., Čerňič, M., Nagode, M., & Kobal Tomc, B. (2019). Analiza izvajanja pomoči na domu. IRSSV 25/2019. Ljubljana: Social protection Institute of the Republic of Slovenia. https://www.irssv.si/upload2/Analiza%20izvajanja%20PND%20za%20leto%202019_30.9.2020_pop2.pdf.
- Kröger, Teppo, Mathew Puthenparambil, Jiby, & Van Aerschoot, Lina (2019). Care poverty : unmet care needs in a Nordic welfare state, 3(4), 485–500. <https://doi.org/10.1332/239788219X15641291564296>
- Kulski, K., Peckham, A., Ashlinder, G., et al. (2018). You've got to look after yourself, to be able to look after them" a qualitative study of the unmet needs of caregivers of community based primary health care patients. *BMC Geriatrics*, 18, 275. <https://doi.org/10.1186/s12877-018-0962-5>
- Kwan, I., Rutter, D., Anderson, B., & Stansfield, C. (2019). Personal care and practical support at home: A systematic review of older people's views and experiences. *Working with Older People*, 23(2), 87–106.
- Laferrère, A., & Van den Bosch, K. (2015). Unmet need for long-term care and social exclusion. Börsch-Supan, Axel, Kneip, Thorsten, Litwin, Howard, Myck, Michał, Weber, Guglielmo (Eds.). *Ageing in Europe: Supporting policies for an inclusive society* De Gruyter, Berlin. <https://doi.org/10.1515/9783110444414>
- Larkin, M., Henwood, M., & Milne, A. (2018). Carer-related research and knowledge: Findings from a scoping review. *Health and Social Care in the Community*, 27(1), 55–67. <https://doi.org/10.1111/hsc.12586>
- Le Bihan, B., Da Roit, B., & Sopadzhyan, A. (2019). The turn to optional familism through the market: Long-term care, cash-for-care, and caregiving policies in. *Europe Social Policy & Administration*, 53, 579–595. <https://doi.org/10.1111/spol.12505>
- Lister, R. (2010). *Understanding theories and concepts in social policy*. Bristol: The Policy Press.

- Maplethorpe, N., Darton, R., & Wittenberg, R. (2015). *Social care: Need for and receipt of help*. Leeds: HSCIC. <http://healthsurvey.hscic.gov.uk/media/33548/HSE2014-Ch5-Social-care-need-and-receipt.pdf>.
- Meagher, G., Cortis, N., Charlesworth, S., & Taylor, W. (2019). In *Meeting the social and emotional support needs of older people using aged care services*. Macquarie University, UNSW Sydney and RMIT University. <https://doi.org/10.26190/5da7d6ab7099a>. <https://researchers.mq.edu.au/en/publications/meeting-the-social-and-emotional-support-needs-of-older-people-us>.
- Official Statistics of Finland. (2019). *Statistical yearbook on social welfare and health care*. National Institute of Health and Welfare. <http://urn.fi/URN:ISBN:978-952-343-388-5>.
- Rodrigues, R. (2020). Caring relationships and their role in users' choices: a study of users of Direct Payments in England. *Ageing and Society*, 40(7), 1469–1489. <https://doi.org/10.1017/S0144686X19000035>
- Rodrigues, R., Filipovic Hrast, M., Kadi, S., Cerar, M., & Hlebec, V. (2022). Life course pathways into intergenerational caregiving. *The Journals of Gerontology*. <https://doi.org/10.1093/geronb/gbac024> Epub ahead of print. <https://academic.oup.com/psychsocgerontology/advance-article/doi/10.1093/geronb/gbac024/6522976?login=false>
- Silvasti, T. (2014). Sisällönanalyysi [Content analysis]. In I. Massa (Ed.), *Polkuja yhteiskuntatieteelliseen ympäristötutkimukseen* (pp. 33–49). [Paths to social scientific environmental research]. Helsinki: Gaudeamus.
- Srakar, A., Hrast, M., Hlebec, V., & Majcen, B. (2015). Social exclusion, welfare regime and unmet long-term care need: Evidence from SHARE. Börsch-Supan, A. Kneip, T. Litwin, H. Myck M. and Weber, G. (Eds.). *Ageing in Europe - supporting policies for an inclusive society* (pp. 189–198) Berlin, München, Boston: De Gruyter. <https://doi.org/10.1515/9783110444414-019>
- Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. New York NY: Routledge.
- Tuomi, J., & Sarajärvi, A. (2009). Laadullinen tutkimus ja sisällönanalyysi. [Qualitative research and content analysis]. Tampere: Tammi.
- Van Aerschot, L., Eskola, P., & Aaltonen, M. (2021). Muistisairaiden ja puoliso-omaishoitajien kokemuksia tuen riittämättömyydestä [Persons with memory disorders and their carers' experiences of unmet care needs]. *Gerontologia*, 35(3), 264–282. <https://doi.org/10.23989/gerontologia.99262>
- Vlachantoni, A. (2019). Unmet need for social care among older people. *Ageing and Society*, 39(4), 657–684.
- Vlachantoni, A., Shaw, R., Willis, R., Evandrou, M., Falkingham, J., & Luff, R. (2011). Measuring unmet need for social care amongst older people. *Population Trends*, 145, 56–72.
- Yeh, S. C. J., & Liu, Y. Y. (2003). Influence of social support on cognitive function in the elderly. *BMC Health Services Research*, 3, 9. <https://doi.org/10.1186/1472-6963-3-9>