



Having much, but not enough – Unmet care needs among community-dwelling older adults in Austria and Slovenia*

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Introduction

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Principle 18 of the European Pillar of Social Rights ensures the right to affordable long-term care (LTC) services of good quality for everyone. The examination of unmet needs of care recipients is an important starting point for the improvement of long-term care policies towards this end. Since LTC policies often embrace the combination of formal and informal care, missing access to either might be seen as susceptible to generate unmet needs. However, even among those who combine both types of care, needs will often remain unmet. The perspectives of older people in need of care and their informal carers offer an important contribution to the detection of unmet needs, a concept which measures their experiences of the care-mix against their respective expectations.

This Policy Brief discusses unmet care needs in community LTC. It is based on findings from the qualitative study of the DET_CAREMIX project carried out in Austria and Slovenia. Older people and their main family caregivers (mostly their adult children) were interviewed on their experiences of caregiving and -receiving. The findings focus on unmet needs in relation to formal care and highlight the significance of unmet care needs even among care dyads who combine informal and formal care in Austria and Slovenia.

Unmet needs were linked to approachability, acceptability, availability and accommodation, affordability and appropriateness. Examples of unmet needs are a lack of services addressing the need to socialise or difficulties in establishing caring relationships with professional carers due to time pressure and staff

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turnover. Unmet care needs demand attention from policy-makers since they hamper healthy ageing and increase care burden for informal carers. In both cases unmet needs may contribute to the deterioration of health of both the care user and informal carer and thus generate additional demand for care.

Background

The LTC policy context in Austria and Slovenia

Austria and Slovenia are both familialist care regimes in which a substantial amount of care is provided as informal care by family members, most of whom are women. Austria's care regime can be described as supported familialism, in which the State provides several measures to enable informal caregiving, namely cash-for-care benefits and 'time rights' in the form of care leave schemes. Slovenia's care regime on the other hand, is characterised as implicitly familialist, in which there is little support for informal carers (Filipovič Hrast et al., 2020). In contrast with Austria, there are no specific paid care leave schemes for carers or cash-for-care benefits, although children are legally obliged to contribute to the costs of their parents' care if the latter cannot afford them. In both countries, those who rely on a mix of care (using formal and informal care) have a wider range of options in terms of care compared to those who only rely on one type of caregiving.

Defining unmet needs

The perspectives of the care dyads can help assess whether the balance between formal and informal care fits the needs of the user without undue stress for the carer

There are different ways to define unmet needs and operationalise them. For instance, unmet needs might be defined in reference to the physical body of the care receiver and strain on the informal carer (Isaacs and Neville, 1976) or to activities of daily living (ADL) and instrumental activities of daily living (IADL) (Vlachantoni, 2019). While the former focuses on care dyads (including both the care receiver and the informal carer) the latter focuses on the care receiver only. Recent social policy research has used unmet needs to describe care poverty as one type of inequality (Kröger et al., 2019). For policymakers, it is of great significance not only to know which needs are unmet, but what types of barriers exist to meeting these needs. We discuss the unmet needs found in the qualitative study of the DET_CAREMIX project by borrowing five terms used to describe barriers to access in healthcare (Levesque et al., 2013) and adding an additional dimension relating to informal care. The first term used by Levesque et al. is 'approachability' which highlights that care dyads have to find a service. Another term is 'acceptability', which describes whether a service is in accordance with the values of different user groups. The third term is 'availability and accommodation' which refers to whether a service



exists (i.e. close enough for use, in a suitable built environment). ‘Affordability’ is a fourth term which points to whether people have the financial resources to use a service. The fifth term is ‘appropriateness’, which focuses on the fit with the care receiver’s needs, i.e. the quality of a service.

While these dimensions taken from healthcare research can help us understand in which ways needs are unmet, the specificity of LTC is that a substantial amount of care is provided by informal carers. Indeed, informal care often compensates for the lack of formal care. While from a distance it might seem that the needs are met, this activity could imply undue strain on the informal carer. We, therefore, consider also unmet needs of informal carers (see also Isaacs and Neville, 1976). This approach can assess whether the balance between formal and informal care fits the needs of the user and, more broadly, the care dyad. It is also possible that the care receiver and the informal carer have conflicting views on the appropriate balance of informal and formal care. Our research might underreport these types of disagreements, because caregivers and care receivers participated in the study, albeit for the most part each were interviewed separately. Despite this possible limitation, some disagreements were reported (i.e. on how much formal or informal care is needed).

Unmet needs from the perspective of older parent-adult child dyads

As research from the DET_CAREMIX project (see Box 1) demonstrates based on the examples of Austria and Slovenia, needs can also remain unmet while there is access to both formal and informal care. Participants described unmet needs in relation to all six dimensions referred to above, albeit with varying degrees of importance.

Box 1: Methods

The qualitative study of the DET_CAREMIX project included semi-structured interviews with 24 care dyads in Austria and 55 care dyads in Slovenia. These dyads included an older parent receiving care and, in most cases, their adult child who was their main caregiver (exceptions were grandchildren and children-in-law acting as main informal carers). Participants were interviewed separately in 158 interviews (with co-presence of the other part of the dyad if requested by them). The interviews were conducted between February and September 2019.

Interviews were transcribed and then analysed with qualitative content analysis. Based on the review of the first interviews, the project team developed a coding framework which was applied to all interviews in both countries. In each country, one researcher coded the interviews and one reviewed the coding. Subsequently, selected codes were summarized and discussed in the project team.



Approachability

Approachability was discussed in both countries as a lack of information for informal carers when it comes to organising care and on how to provide good quality care. In Slovenia, it was usually the carers who organised care and gathered necessary information, initially often through informal networks. In Slovenia, it was put forward in some cases that, when experiencing the sudden onset of needs, carers and their family members were confronted with long waiting lists and therefore with problems in getting enough help at the start. The fact that problems in accessing information about organising care was mainly expressed by informal carers in both countries, is probably linked to the fact that all interviewees had a mixed care arrangement, i.e. all care receivers could rely on informal care givers to take on the organisation of care if needed. However, also in this group of interviewees, some care receivers took on a more active role in organising care.

Acceptability

The topic of acceptability was rarely present in the narratives of dyads, but still referred to in discussions around bodily care of intimate nature. In these contexts, the gender of the caregiver, but also the establishment of caring relationships that arose with time were considered important factors for satisfaction with care. For example, while same gender care was clearly the preferred option for bodily care, some female care receivers could come to accept bodily care from a male formal carer despite initial hesitations after a trusting relationship had been established.

Availability and accommodation

Unmet needs are linked to LTC systems in Austria and Slovenia still focusing on service delivery rather than addressing the well-being of users and carers

Availability and accommodation were described by the lack of different types of bodily care (i.e. hairdresser, manicure) and household help (cleaning) within the scope of formal LTC provision in Austria. However, needs that should ideally be addressed by formal care went beyond help with these tasks. There was a range of needs around socialising and emotional well-being that were unmet and affected psychological well-being. Informal carers proposed different ways to meet these needs, such as meeting with peers, using a visiting service or mental health support.

"... whether [a formal carer] has training or not, but targeted mental health counselling I would find very good. But this is not foreseen. One has to pay for it."

Informal carer, Austria



Care receivers were more likely to highlight that they would want to undertake more activities such as attendance of events, or going on trips or for walks. To engage in these activities, they would need help from someone else. In Slovenia, care dyads also described a lack of innovative forms of specialised care, namely for people living with dementia.

Both in Austria and in Slovenia, certain types of formal carers were not allowed or not able to carry out specific medical or nursing tasks, with the consequence that informal carers had to take over. Wound dressing or bandaging of legs as mentioned in the quote below were such examples.

“Another thing that is very inconvenient is that they do not do the bandaging of the legs. At the start, they did that. But then it was said that it is too medical and they do not do that.”

Informal carer, Slovenia

Affordability

Financial barriers to accessing formal care were not mentioned very often, although examples were given in both countries. In Slovenia, some people highlighted that they would have needed more care than they received, but were financially constrained.

“Yes, they would need additional help in the afternoon, but there is a financial problem.”

Informal carer, Slovenia

The few complaints in Austria about the lack of affordability concentrated on more highly skilled carers or day-care centres and leisure activities linked to day-care. However, several informal carers in Austria reported that they contribute out of their own pocket to top up the LTC allowance or to pay for additional care services – a clear hint at the potential for unmet needs without this contribution. Again, it is worth bearing in mind that our sample of dyads included only users who received both formal and informal care, thus denoting at least some capacity to pay for care.

Appropriateness

Appropriateness was arguably the most often cited reason for unmet needs in relation to formal care services in both countries. Examples were often linked to the organisation of formal services, in particular regarding limited time spent



Appropriateness was described as a problem with formal care services by several interviewees often linked to how formal services were delivered or organised

with the formal carer. For instance, specific activities such as leaving the house with the formal carer have been described as impossible. Also, formal carers would not arrive at the same time every day, which restricted the person in need in her activities, i.e. by not being able to use a day care centre because of the unpredictability of the arrival of formal carers. The lack of spontaneous support from formal carers was another example linked to the issue of time.

Moreover, the frequent turnover of staff was viewed as impacting negatively on the quality of the care provided in both countries.

"B: ... since April they've had a restructuring, they don't admit it though. Then, it can be that during one day, three times someone else is coming. And this seven times a week and of course, since then mum is a bit ... I don't know how to say, not good somehow. She's not like that, mum.

A: Is it too much for her? Do you think so?

B: Well, mainly, I think yes, because she doesn't know them, they are coming, they don't know what to do."

Informal carer, Austria

Some interviewees also mentioned lack of trust in caring relationships, sometimes linked to staff turnover and the inability to have the same professional carer visiting because of the organisation of care work by providers. Care dyads also described examples of formal care not addressing the needs of the user in the way activities were carried out, i.e. by feeding the care receiver rather than letting the person herself eat because of time pressure.

Informal carers' needs

While the needs of informal carers were not the main focus of the qualitative study, these were mentioned too. As described above, caregivers' needs emerged in relation to the difficulties of finding information needed for organising care. In both countries, their unmet needs also surfaced in the description of care burden (i.e. not being able to see friends anymore, not having any leisure time anymore, not being able to go on vacation).

"Well, in short, I have to say as next of kin, even more if this happens as suddenly as it happened with mum, one is totally overtaxed and, well, I haven't had any private life ever since."

Informal carer, Austria



Conclusion

Developing and refining measures for unmet needs and monitoring their occurrence is an important area to evaluate current care policies and to improve future care. Involving older people in need of care and their informal carers in this assessment provides an opportunity to further include older people themselves in debates around ageing well, thus contributing to healthy ageing in the context of LTC needs.

Unmet needs also reflect potential organizational shortcomings among providers and structural problems such as staff turnover and underfunding of care

Results highlight that even when combining formal and informal care this does not safeguard against unmet needs in familialist countries. Narratives point to gaps in addressing some types of needs in both welfare systems analysed. Particularly among these were social and emotional needs that often remained unaddressed in both Austria and Slovenia. Perceived unmet needs were also linked to how care delivery was organised, especially regarding the time and daily routines of users. This should merit attention from commissioners and (formal) providers of care in both countries. Similar to other contexts (cf. Rodrigues, 2020, for a case study on England), unmet needs also reflected gaps and constraints in building and sustaining formal caring relationships that are fundamental to the quality of care. One such example are frequently changing formal carers because of the ways in which providers organise work for formal carers. Unmet needs thus reflected wider constraints and structural issues within the care systems of Austria and Slovenia, namely, high staff turnover and insufficient funding that led to instances of ‘time-trial care’, in which carers had no possibility to deviate from their assigned tasks to meet spontaneous needs. It is also worth mentioning that unmet needs were sometimes referred to as one of the triggers for informal care provision, sometimes at the expense of labour market attachment of carers or their own well-being.

It can be assumed that people in need of care and their carers who are very distressed because of unmet needs are less likely to participate in research about their experiences of care receiving and -giving. This implies that unmet needs are probably underreported in the current study.

While the use of formal care will contribute to reducing the burden of informal carers, it does not guarantee that needs are met. Since informal carers will often cover what is left unmet by formal care as best as they can, unmet needs can remain hidden if the situation of the informal carer is not considered in the assessment of needs and the measurement of unmet needs. This is likely to be the case in familialist care regimes such as those in Austria and Slovenia.

Policy recommendations:

- 1) Member States are requested to implement Principle 18 of the European Pillar of Social Rights, i.e. to ensure the right to affordable long-term care services of good quality for everyone. In doing so, **evaluation of unmet needs in LTC** should include an assessment of care burden carried by the informal carer. Moreover, the specific barriers to meeting the needs of the care dyad described in this Policy Brief should be addressed.
- 2) LTC is about more than just service delivery or addressing ADLs and IADLs only. **Socializing and addressing the psychological well-being of users** is key, especially in face of growing social isolation and loneliness and should be included in the 'basket' of care offered by public LTC systems.
- 3) Unmet needs are linked to **how care is organised** by providers or contracted by public authorities. Staff turnover seems to be both a key determinant of and a measure of quality of care delivered. Staff turnover should therefore be included as a performance measurement indicator linked to financing or performance assessment.

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