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RESEARCH ARTICLE

Maintaining autonomy: How older persons with chronic conditions and their significant others interpret, navigate, and overcome everyday difficulties

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ABSTRACT

Background: The vast majority of older adults live in their own homes. Many of them live with chronic conditions that lead to activity limitations and participation restrictions. To support them adequately, we need to better understand how they cope with everyday difficulties.

Aim: To identify and examine difficulties in everyday life older people with chronic conditions who live in private homes face and how they and their significant others interpret, navigate, and overcome these difficulties.

Material and Methods: We conducted a focus group interview with 10 participants including eight older adults with chronic conditions and two of their significant others. We then transcribed the interviews verbatim and thematically analysed them.

Results: We generated the three closely interrelated themes *struggling not to lose control, a shifting balance between resources and environmental challenges,* and *negotiating independence and interdependence*. Participants interpreted the difficulties they faced as multicausal. Their main goal was maintaining autonomy, agency, and a positive identity. They employed individual, creative strategies to achieve these goals.

Conclusions: Older persons with chronic conditions prioritise autonomy and agency in order to maintain a positive identity.

Significance: Interventions to support older persons with chronic conditions should centre their priorities and build on their creativity.

Introduction

The vast majority of older adults in Europe live in private homes. In 2011, European Union census data showed 96.4% of persons over 65 (83 million people) and 86.7% of persons over 85 (9 million people) living in private homes [1]. In Switzerland, data from the early twenty first century show 91.5% of people over the age of 65 and 80% of people over the age of 80 living in their own homes [2]. Considering current demographic trends, it can be projected that by 2030 there will be almost 2 million people over the age of 65 living in their own homes in Switzerland alone, of whom approximately half a million people will be over the age of 80 [3]. In the European Union, according to projections, the corresponding numbers may be up to 120 million people over the age of 65

living in private homes, of whom 32 million will be over the age of 80 [4].

Many of these people will be living with one or more chronic conditions. In a large-scale cross-sectional study among community-dwelling Swiss adults 65 years old or older, 76.6% were found to be suffering from multimorbidity, defined as the presence of two or more chronic conditions [5]. People living with chronic conditions commonly experience limitations in their activities of daily living, as well as restrictions in their participation at home and in the community [6,7]. Physical and cognitive impairments, activity limitations, and participation restrictions are, therefore, highly common in this group, although not ubiquitous. The presence of chronic conditions associated with difficulties in everyday life should not be confused with frailty, defined as an

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increased vulnerability to disproportionate deterioration of health status after a stressor event [8]. Not all older people with chronic conditions are frail. While some chronic conditions or combinations thereof may facilitate frailty, similarly, not all frail people are chronically ill, though there is considerable overlap [9]. In this study, we are interested in older persons with chronic conditions who live in private homes and experience some impairment in everyday life, frail or not.

In order to design interventions to support older adults living with chronic conditions to improve or maintain their quality of life, autonomy, and social participation, we need to know more about what difficulties they encounter in everyday life, how they interpret them, and how they navigate and overcome them. This type of knowledge is relevant to all health and social care professions that work with older persons, as well as to policy makers. While there has been some research done in this area, it is mainly focused on how people navigate and relate to their home, as in house or apartment, in the light of age-related functional decline [10–13]. Some of the most salient points in the literature are the importance that is placed on independence and autonomy [10,12] and, conversely, the ambivalence towards outside, especially professional, help [11,13]. In an ethnographic study of British older adults living at home, Ewart & Luck described how participation outside the home was very important, but often also difficult for their participants. These older adults framed their problems as determined mainly by age-related physical health problems, but also mentioned barriers in public space [11].

While the challenges older people face in order to maintain independence are well described in the literature, there has been less of a focus on the ways in which older people actively navigate these challenges. Romaioli and Contarello note that ageing is often seen as a process of physical and mental decline, and older persons are not necessarily seen as people with their own agency [4]. Nicholson et al. however, in another British study of the experiences of frail older people living at home, observed an everyday creativity in their participants that they described as 'relational' and which allowed them to adapt to changes in their living situation and environment [13]. Complicating matters, the elderly participants of Kruse et al.'s [14] qualitative study asserted their autonomy and independence specifically by resisting advice to adapt elements of their homes in a way that would reduce falling risks and, therefore, support their independence in the long term – a sentiment mirrored by the participants in a similar earlier study by Simpson et al. [15]. Both behaviours, active adaptation and refusal to adapt, could be viewed as the exerting of agency. This fits with an understanding of agency as a creative, relational process whose meaning can change in the context of different situations [16].

Furthermore, little is known about if older people with chronic conditions also understand difficulties in everyday life as determined mainly by age-related physical health problems, if they instead feel these difficulties are mainly caused by an inaccessible or unsupportive physical or social environment, or a combination of both, and how they actively navigate these difficulties.

Two thirds of Swiss adults 65 years old or older live with a significant other [17]. Older couple's everyday lives are often intrinsically intertwined [18,19], and the importance of including significant others when offering interventions for chronic illness management has been described in the literature [20]. For this reason, it seemed important to us to include the viewpoints of significant others of older people with chronic conditions. Hence, the aim of this study was to add to the existing literature by identifying and examining the difficulties in everyday life older people with chronic conditions who live in private homes face and how they and their significant others interpret, navigate, and overcome difficulties in everyday life.

Material and methods

Theoretical background

The theoretical background of this study is situated in a critical realist paradigm. While we assume that through our inquiry we can access the experiences and attitudes of our participants, we do not expect these experiences and attitudes to necessarily be inherently 'true' characteristics of the participants, but rather socially located and mediated through language and culture [21]. Because we assume participants' experiences and attitudes to be social located and thusly mediated, we need to engage with them hermeneutically to try and gain an understanding [22]. We strive to achieve this through a method of analysis that relies on the hermeneutic circle – moving between the parts and the whole of the text in an iterative way [23].

Study design and setting

The participants of this study were inhabitants of a suburban community in Switzerland. We chose to use

focus group methodology as it was expected that older persons would more readily voice their struggles and share their views with a group of peers than with a single researcher [24]. This methodology is in accord with our critical realist theoretical orientation, as it understands experiences and attitudes as socially located [21]. To allow for a variety of viewpoints, we sampled participants purposively to reflect the diversity of the population in question in terms of socio-economic background, age, and physical impairment [25], although with no claims of representativeness. The authors planned and conducted the focus group together. Both authors were experienced in conducting focus groups. A second focus group with local stakeholders involved in the topic of older people with chronic conditions living at home was conducted in tandem. The results of this study will be published elsewhere [26]. The regional ethics board of Northwestern and Central Switzerland reviewed the study protocol and deemed it not in need of formal ethical approval (Project-ID Req-2019-01159).

Sampling

Using purposive sampling, we recruited participants from the client roster of a local home care organisation. An employee of the organisation contacted potential participants and provided verbal and written information about the study. The employee was instructed to sample participants to reflect the diversity of this population in terms of socioeconomic background, age, and physical impairment. The first author then contacted participants who agreed to take part by telephone and gave them additional verbal information on the aim of the study, what participating in the focus group would entail, how the data would be used, and their right to withdraw from the study at any point. The participants who fulfilled inclusion criteria and agreed to take part in the study provided basic sociodemographic data over the phone.

Participants then received a written invitation through the mail. On the day of the focus group, they gave written consent upon arrival at the focus group site. Criteria for participation were:

- 65 years old or older
- living at home (i.e., not in an institution)
- living with one or more chronic conditions (i.e., multimorbidity)
- experiencing some impairment in everyday life
- using a domestic home care service
- or: being the significant other of a person who fulfils the first five criteria

The exclusion criteria were:

- cognitive/sensory impairment seriously impeding participation in a focus group
- knowledge of German not sufficient to actively participate in a focus group

Participants

The group of 10 participants included four men and six women between 65 and 89 years of age, with a mean age of 80 years ($SD = 8.4$). Five participants had moved to a new home in the last 5 years, while the other five had lived in their current homes between 8.5 and 48 years. Like the majority of the Swiss population [27], most of the participants lived in rented apartments, while two participants, a couple, were house owners. The participants came from diverse socioeconomic backgrounds, with four of them receiving supplementary benefits to their government pension (see Table 1). Two participants, participants B and H1, were included as significant others of older persons with chronic conditions. Our reasoning behind including only two significant others was that we felt that while their view should be included, the focus of our study

Table 1. Participant characteristics.

Participant	Age in years	Gender	Type of housing	Living in current habitation in years	Self-rated health (0-100)	Self-rated impairment	Receiving supplementary benefits
A	73	m	apartment	3	80	light	no
B	68	m	apartment	3	90	none	yes
C1	86	f	apartment	0.17	80	light	no
C2	86	m	apartment	0.17	80	light	no
D	89	f	apartment	8.5	70	light	yes
E	78	f	apartment	18	70	severe	no
F	65	f	apartment	10	65	light	yes
G	81	f	apartment	0.17	70	severe	yes
H1	85	m	house	48	90	none	no
H2	86	f	house	48	60	severe	no

Note: f = female, m = male.

was on persons with chronic condition themselves. Among the participants were two married couples, participants C1 and C2 and participants H1 and H2.

Data collection

Before the interview, the participants provided some sociodemographic information and answered two single questions on their self-perceived health ('On a scale from 0-100, with 100 being perfect health, and 0 being the worst health imaginable, how would you rate your own health?') and their self-perceived impairment ('In your everyday life, would you describe the extent to which you are impaired when performing activities that are important to you as a) severe, b) medium, c) light, or d) none'). We collected the main data in one two-hour focus group interview. The interview took place in a meeting room provided by the home nursing care organisation mentioned above. To facilitate a discussion on difficulties in their everyday lives and their understanding and interpretations of these difficulties, we designed the interview guide specifically to elicit such statements. We formulated three general questions:

- Which difficulties in your everyday activities do you or your spouse experience as an older person with chronic conditions living at home?
- What has helped/is helping you and/or your spouse to overcome these difficulties?
- What kind of support would you wish for in order for your and/or your spouse's everyday life to become easier or more satisfying?

Participants were encouraged to not just enumerate, but describe everyday difficulties, their strategies overcoming them, and the support they would welcome.

The authors conducted the focus group interview. It lasted 120 min, with a short break after the first 60 min. The interview was recorded digitally and transcribed verbatim, resulting in a transcript of approximately 30 pages. The first author double checked the transcript for accuracy. Audiofiles and transcript were saved on a secure server.

Data analysis

We analysed the transcript following the thematic analysis procedure laid out by Braun and Clarke [28] (see Figure 1). As a first step, the first author familiarised himself with the data by listening to the recording and rereading the transcript. Secondly, going through the text line by line, the first author identified units of meaning (i.e. a statement usually one or two sentences long that represented a single idea or concept [29]). These units were then inductively assigned codes in order to describe their meaning. To increase credibility, the second author recoded a portion of the transcript in the same manner, without prior knowledge of the codes already generated by the first author. The authors then compared and discussed differences between the codes generated. While there were no basic disagreements, this discussion was fruitful to the authors' understanding of how these codes were connected, which informed the next step. In a third step, the first author reviewed the coded data and clustered the codes into four common themes, based on relationships, similarities, and latent ideas that we identified in our analysis. In a fourth step, the first author examined the themes' consistency with the data as a whole. To increase credibility, both authors discussed the themes. In an iterative process, step three was then repeated, the themes were revised and collapsed into three themes, also repeating step four to ensure the themes'
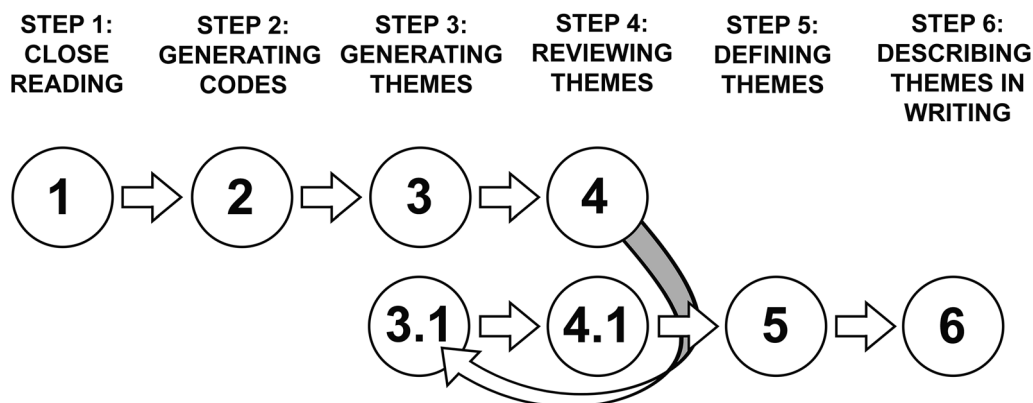

Figure 1. Iterative process of thematic analysis applied in this study. Based on process of thematic analysis described by Braun & Clarke [23]

congruence with the text as a whole. Finally, in steps five and six, the first author defined, named, and described the themes in writing, articulating the latent ideas identified in the clusters of codes and the relationships between them.

Results

We identified three closely interrelated themes: *struggling not to lose control, a shifting balance between resources and environmental challenges,* and *negotiating independence and interdependence.* We describe these themes in more detail in the following sections.

Theme 1: Struggling not to lose control

Participants regularly experienced everyday difficulties that impeded their autonomy, in their homes as well as in public spaces. They perceived the reasons for these difficulties as multifactorial, based as much on individual impairments and attitudes, barriers in the physical environment, lack of social support, and structural barriers. Everyday difficulties arose in situations where the participants' available resources did not match the challenges that their environment posed to them. Failing to meet these challenges meant not being able to do the things they want or need to do, when to do them, or in the way they would like to do them. This failure resulted in feelings of powerlessness and loss of control. However, participants tried to overcome these challenges in creative ways, and by mobilising the social, financial, and structural resources available to them.

Loss of control took place when participants were not able to do things they wanted or needed to do, when they wanted to do them, or in the way they would like to do them. For instance, Participant F was not able to do certain difficult household tasks and did not feel comfortable asking neighbours to help her. She wished she had someone to turn to 'where I don't have to ask for it down on my knees'. Participant G, who uses an electric wheelchair, was unable to access her balcony by herself, and had trouble opening her own front door, which opens towards the inside.

In these cases, the participants' resources did not match the challenges their environment posed to them. This included physical barriers in the home (e.g. furniture placement, a lack of navigating space, thresholds between rooms, placement of outlets, heavy front doors) - sometimes even in apartments that were supposedly 'barrier-free' – and in public spaces, especially related to wheelchair and rollator mobility (e.g. the absence of ramps, for instance around construction sites). Especially barriers in public space

were largely perceived as outside of the control of participants.

An important resource that was sometimes lacking was social support. While some participants stressed the importance of family and neighbourhood networks, others insisted that there should be more options for people who do not have these informal social resources. Some participants were worried by what they perceived as a decline in volunteering in this area. More formalised resources were partly appreciated – like the Swiss home health care system – partly problematised. For instance, paratransit mobility services (i.e. transport services for people who cannot use public transport) were characterised as limited, not allowing for spontaneity, and expensive. Also, according to the participants, information about support services for older people was not always easily available. Some participants remarked on how the social insurance system, which is designed to be a resource for people with impairments, failed to do so in certain instances. Participant G recounted her experience:

> And the worst for me, during my whole time as a disabled person, was that I had to pay for my [electric] wheelchair myself because I was already at AHV age [senior's pension]. […] thankfully, thankfully I had a friend who gave me the money. I wouldn't have had the money. […] And that's the weirdest thing, and I tell young people with problems, if you have IV [disability pension] and need a wheelchair, get it before you have AHV and not after. Because then you are still entitled to it.
>
> (Participant G)

Not being able to pay for the electric wheelchair she needed, participant G struggled not to lose control over deciding what things she wanted or needed to do and how and when to do them. Structural resources were not designed to help her retain this control. She had to mobilise social resources: a friend who paid for the wheelchair.

Participants did not just passively experience many of these difficulties, but engaged with them actively in order to navigate or overcome them, regain control and exert agency. Participant A remarked on the importance of keeping physically and mentally fit, for example to avoid falls. Some participants made the active choice to move into barrier-free apartments. Others, who had the necessary financial resources, adapted their homes to their changing needs (e.g. installing a stair lift, levelling out the garden). Participants used different adaptations (e.g. bath boards, rearranging rooms, removing carpets), assistive technologies (e.g. emergency call watches) and behavioural

strategies (e.g. placing keys with acquaintances,) to increase their autonomy and feeling of security. Generally, participants experienced adaptations not as a threat to their autonomy and identity, but as a means of empowerment that helped them maintain a positive identity as an autonomous subject. However, this sometimes involved finding solutions that fit with their identity and rejecting ones that did not:

> I felt like I did not like the [emergency call watch], so I have a cordless phone in each room. That's five phones right now, they are always charged, and if I am on the floor in one room, I can take the phone and call one of three acquaintances who I gave a key to so they can enter my apartment.

> (Participant A)

Also, participants took advantage of formal support (e.g. home nursing, meals on wheels) and, if available, informal support (family, friends, strangers on the street).

In summary, situations where the participants' resources did not match the challenges that their environment posed to them could lead to a loss of control over doing the things they want or need to do, when to do them, or the way they would like to do them. Participants tried to navigate and overcome these challenges in individual, creative ways that they often understood as examples of 'personal initiative', as well as by mobilising the social, financial and structural resources available to them.

Theme 2: A shifting balance between resources and environmental challenges

The balance between participants' resources and the challenges their environment poses to them was not fixed, but can be described as always shifting, because both the environment as well as a person's resources are always subject to change. To stabilise this balance after an event that effects such a change, people needed to take action and mobilise available resources.

For some participants, there was an incident that occurred abruptly and created an immediate shift in this balance between resources and challenges. Participant E, for example, suffered two falls that suddenly made navigating her environment more challenging for her and made it necessary for her to immediately mobilise additional resources (e.g. home health care, familial support). For participant A, who is a wheelchair user, the sudden death of his spouse, who provided a lot of support for him, necessitated him to reorganise his life on a practical level, an experience that he describes in the following quote:

> In the last four years, I had to learn a lot. It was always taken for granted that the trash was taken out, that the laundry was made […] I can do a lot of things myself, but for hanging a lamp or carrying a heavy flowerpot onto the balcony and stuff like that – I have built a network of people that I can call. They won't be here within the hour or anything, but you can organise it, somebody will come and do it.

> (Participant A)

For other participants, instead of an abrupt event, it was a slower, steady decline in physical functioning that eventually required them to take action. For instance, participants C1 and C2 described an accumulation of health issues over the years (i.e. a heart attack, pulmonary oedema, various operations) that gradually created a need for adaptations and additional support. For participants G and H2, it was a progressive chronic condition.

The decision to take action and either adapt the current home or move to a better suited living arrangement was partially determined by the financial resources that were available to the participants. For people living with a significant other, it was also subject to negotiation within the couple. Participants H1 and H2 eventually decided to adapt their home, a decision that had to be worked out between them:

> In our case, we had no other choice than installing a stair lift. Or leaving the house and moving to a place with an elevator, but leaving wasn't really an option. Well, it was for me, but not for my wife [laughs]

> (Participant H1)

In contrast, Participants C1, C2 and G decided to move to a barrier-free apartment. Although they reported that they sometimes missed their old homes, they also stated that they were generally happy with this decision.

Whether the participants chose to adapt their existing homes, or to move to a barrier-free apartment, they aimed - and generally succeeded - to stabilise the shifting balance between resources and environmental challenges to a certain degree, even if it meant accepting some change.

To summarise this theme, it can be stated that most of the time, shifts in the balance between resources and environmental challenges in the lives of the participants were put into motion by health issues. These issues could be either sudden, abrupt events, like falls, or more gradual or cumulative health challenges (e.g. chronic conditions). To stabilise the balance between resources and environmental challenges, participants again needed to take action (i.e. exert agency) and

mobilise their available resources, for instance by adapting their physical and/or social environment, or by moving to a more age-friendly environment.

Theme 3: Negotiating independence and interdependence

Participants constantly negotiated independence and interdependence. While on one hand, they emphasised 'personal initiative' and personal responsibility as a core characteristic one needs in order to deal with everyday difficulties, on the other hand they pointed out that social and financial resources were unevenly distributed and mediated how 'independent' one could really be.

The idea that personal initiative and personal responsibility is important was often articulated in a normative way: as how people *ought to* be and what could be *expected* of people. Personal initiative and personal responsibility were described as desirable character traits and contrasted with the expectation that others should take care of oneself, a supposedly less desirable character trait. At the same time, participants pointed out as that some people have trouble accepting help or asking for support, which they also perceived as a problem. These two statements are in somewhat of a tension to one another: the first one, stressing the importance of personal responsibility, focused on *independence*, the second, pointing to the importance of accepting support, focused on *interdependence*. This apparent tension is also illustrated by the following quotes:

> You have to do this for yourself and look, what are my needs and how can I meet them […] it isn't the city's job to go to people and ask them what they need.
>
> (Participant A)

> Many people can't accept any outside help.
>
> (Participant E)

Most participants explicitly saw themselves as independent or striving for independence. Participant G, for example, described herself as *'the type of person who tries to be extremely independent'*, while Participant E voiced how she hoped to be independent again when she recovered from her fall-related injuries. Participant F even remarked that she believed *'[…] when you live alone, you have to run [it] like a small business'*.

At the same time, participants did actually take advantage of many different forms of formal and informal support. First and foremost, they named professional home care nursing and the family as important support systems. Also, wider social support systems (e.g. friends, acquaintances, neighbours) were perceived as crucial. While some saw it as a part of personal initiative and personal responsibility to build up and nurture these informal connections yourself, the participants generally acknowledged that not everybody has the necessary resources and opportunities for this. Similarly, while some participants took 'personal initiative' by adapting their homes (e.g. installing a stair lift), they could only do so because they had the necessary financial resources.

A possible resolution to the tension between interdependence and independence is illustrated by a statement that Participant A made. He expressed how not having the ambition to do everything himself freed him up to focus on things that are important to him. This statement points towards a valuing of autonomy rather than independence.

In summary, while participants stressed the importance of 'personal initiative' and personal responsibility, they at the same time granted that the ability to do so depended to a large degree on a person's access to resources. They also relied on formal and informal support themselves, although they thought that other people may struggle to accept help. While there are underlying tensions between their valuing of independence and personal responsibility on one side and the acknowledgement of interdependence and a need for support and access to resources on the other, participants were able to reconcile these contradictions.

Discussion

In this study, we aimed to examine the difficulties in everyday life older people with chronic conditions who live in private homes face and how they and their significant others interpret, navigate and overcome those difficulties. In the following, we will discuss the common threads within the three interrelated themes *struggling not to lose control, a shifting balance between resources and environmental challenges,* and *negotiating independence and interdependence:* the reclaiming of *agency* and its relationship to autonomy and occupational identity. With Wray [16], we view agency as a creative, generative, and relational process that people engage in and whose meaning isn't fixed, but contextually situated. We understand autonomy as 'the ability and opportunity to act in accordance with one's values, unfettered by coercion, duress, restraint or deceit' [30]. We also rely on the concept of occupational identity, which has been defined as 'the sense

of who one is and wishes to become as an occupational being generated from one's history of occupational participation' [31].

We found that the participants of our study perceived everyday difficulties as caused by multiple factors, including physical health problems, lack of accessibility in the physical environment, lack of a social support system and structural problems (e.g. regarding social insurance). With this interpretation, they are going beyond the notion that difficulties in everyday life are 'determined primarily by the extent of their physical deterioration' [11, p. 36–37], and are aligning more with the concept of ageing well as based on a person-environment interaction that has been first suggested by Lawton and Nahemow [32] and, more recently, by Wahl et al. [33]. Also, by identifying the influence of external circumstances, they generate a space of agency for themselves to navigate or overcome these difficulties. While physical deterioration can, at best, be managed, these external circumstances are often subject to change.

The participants use this space of agency to mobilise all the resources available to them – financial resources, social support networks, health care services, but also their personal creativity in coming up with strategies of how to navigate or overcome everyday difficulties. This type of creativity has also been reported on by Nicolson et al. [e.g. 13] in their study on the experiences of frail older people living at home: 'This creativity however is not the figurative creativity of art or music […] rather it is a relational creativity underpinned by the capacity to connect to their changing circumstances'. Creativity, in Wray's [16] view, is also a basic source of individual agency.

The participants also exert agency by making decisions about their living circumstances that go beyond simply trying to stay in their long-time homes at all cost, but can involve a conscious choice to move to a place more suited for their needs in order to maintain their autonomy. By enacting this agency in occupations (e.g. adaptations of the home, looking for or moving to another home), they enact their own independent, autonomous subjectivity. This is in contrast to other studies who found that some older people tried to maintain independence «by managing activities *in the way they always had been performed* [emphasis added], and being successful in this respect contributed to a preserved picture of being an independent person» [12, p. 18; see also 14,15].

While, as Romaioli and Contarello write, 'the Western idea of agency with regard to older people tends to focus, paradoxically, on the methods that they adopt to delay growing old and to address the decline linked to age' [34, p. 196], we find a different kind of agency here, again defined as 'the way chosen by a person to give meaning to his/her actions and to the possibility of actively planning his/her own future' This notion aligns with Lawton's [35] *environmental proactivity hypothesis* suggesting that 'older adults are not simply pawns of their environment but can proactively change environments in order to meet their own needs and to maintain independence' [33, p. 309], and with the idea that agency is enacted in everyday occupations [36].

But while our results stress the importance of agency, they also point towards the connections of agency to autonomy and identity. Haak et al., in their study of what constitutes independence in the home for older single-living people in Sweden, identified an age-related 'shift in focus from independence to autonomy, that is, being able to govern is very important even if receiving help is acceptable. Autonomy is not synonymous with independence […] it is possible to be dependent yet experience autonomy» [12, p. 22]. This distinction of autonomy from independence, which has also been described by Hammell [37], is visible in our data as well. While they stressed 'personal initiative' as important, the participants did not perceive a contradiction between their self-view as 'independent persons' and accepting formal and informal support. Even Participant F, who struggled with 'asking' for help, would have gladly accepted it if it would have been framed as something she is entitled to. While pursuing 'independence' understood in a traditional sense as 'being able to do things for oneself, to be self-supporting and self-reliant' [38, p. 353] can actually curtail the choices of people with impairments, accepting support can extend those choices and grant people more autonomy, as long as they remain in control. There is, therefore, a strong interrelation between autonomy and agency, defined as 'the way *chosen by a person* [emphasis added] to give meaning to his/her actions and to the possibility of actively planning his/her own future' [34, p. 197], with autonomy referring more to the ability to choose and be in control, and agency as the possibility of self-directed action. This dyad features prominently in our data, and it seems to be at the heart of how older people with chronic conditions and their significant others interpret, navigate and overcome difficulties in everyday life. While maintaining autonomy seems to be the main goal, agency, at the same time grounded in and furthering this autonomy, is the act of performing empowerment. The extent to which 'personal initiative' is stressed by the participants, and statements about how they

want to *be* a person that's independent, illuminate the strong connection that autonomy and agency have to identity. Especially the connection between agency and identity is reminiscent of the relationship between doing (i.e. agency), being, and becoming (i.e. identity) that has been proposed in the occupational science literature [e.g. 39–43]. Hansson et al., based on a concept analysis of *occupational identity*, remark that in the process of occupational identity construction 'the established sense of self is expressed through individual agency or doing and is also constructed by way of doing' [44, p. 6]

Limitations

This study has some limitations. For one, it consists of only one focus group, and the analysis is, therefore, based on a limited number of participants. The choice to limit this study to only one focus group was a pragmatic one based on the available resources. The results of the tandem study [26] will, however, add the perspectives of other stakeholders and thus somewhat complement the data of this study. It is possible that our questions somewhat guided participants' answers, however we tried to minimise this by keeping the answers as open as possible. While the questions presuppose difficulties in everyday life, this is also an inclusion criterion for participants. Also, the voices of older people with a migrant background and/or with cognitive impairments – both sizeable groups that are likely to have very specific experiences – are not present. This was partly for methodological reasons (language skills and/or cognitive fitness to participate in a focus group). This omission should be rectified in future studies on this topic. We have aimed to strengthen the trustworthiness of our analysis [45] through prolonged engagement with the data, regular peer debriefing, and researcher triangulation [46]. Our iterative approach to the data, based on the hermeneutic circle and laid out in Figure 1, included the formulation and then reformulation of themes, moving between single codes, larger themes, and the transcript as a whole, and helped us sharpen our analysis in the process.

Conclusion

In this study, we aimed to identify and examine difficulties in everyday life older people with chronic conditions face and how they and their significant others interpret, navigate, and overcome these difficulties. We found that older people with chronic conditions living at home face everyday difficulties when their resources do not match the challenges their environment poses to them. We also found that they and their significant others have a nuanced understanding of the difficulties they face in everyday life, and that they creatively enact agency to navigate and overcome these difficulties. While there are different issues that make it necessary for them to adapt and make changes to their occupations and living circumstances, the common goal of these changes and adaptations seem to be to first and foremost to maintain *autonomy,* at least in the context that we were examining. For occupational therapists and other health professionals who want to support them, it is important to recognise their agency and their understanding of the everyday difficulties they face, without tacitly ascribing them their own interpretations. Also, the creativity that older people with chronic conditions use to navigate or overcome their difficulties should be recognised and built upon. Future studies could examine if these issues are taken into account by existing services, and how health and social care services can be designed to foster older persons' autonomy and benefit from their creativity. Also, future studies should include a more diverse population of older people, namely persons with a migrant background and/or older people with cognitive impairments and their significant others, and adapt their study design accordingly.

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