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# The Home Care Home – An Un-Total Institution. When the Care Home Logic Permeates the Private Space

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**Abstract.** This article examines how the provision of home care services impact older individuals in Sweden, focusing on how it may subtly institutionalise their daily lives. Domiciliary care is found to negatively impact users' individuality and independence, contrary to initial intentions of offering an emancipatory alternative to nursing facilities.

The study uses Goffman's concept of total institutions, operationalised by identifying aspects of everyday life within which institutionalisation manifests itself, including meals, daily rhythmics, and lifestyle choices.

For this article, the experiences of home care users in Sweden were collected in 34 qualitative interviews and 15 observations with respondents aged between 68 and 96 years. The material was examined using theory-driven thematic analysis.

Results show that while some care users find comfort in the structures imposed to their lives, many are faced with limitations related to the tight, minute-timed scheduling and the assembly-line style of care provision. The constraints affect everyday life choices related to eating, sleeping hours, hobbies, and the sense of home, which are all influenced by the care organisation's work regime and scheduling.

The analysis concludes by proposing the term "home care home". This designation indicates the challenges to individuality entailed in the home care rationale, while acknowledging that the influence on users is "less-than-total", as compared to typical institutionalising environments such as prisons or hospitals.

While a total institution is commonly understood as a spatial structure, it also functions as a logic acting regardless of physical constraints – for instance, in a person's home. Moreover, the study suggests that this logic may be at work anywhere within large-scale production of human services.

In summary, this article addresses the individuality-eroding force ingrained in home care provision and emphasises the need to strengthen users' influence on care provision in order to increase their independence.

Keywords: Home care, institutionalisation, total institution, ageing in place, everyday life

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#### Introduction

Swedish home care services, initiated as a remedial measure to counter nursing homes' institutionalising effects, are framed as an empowering alternative, promoting "ageing-in-place" to uphold individuality, and the significance of one's home environment. However, this article reveals that an institutionalising logic subtly permeates care users' day-to-day life, imbuing their homes with the characteristics of a total institution, and explores care users' responding actions and behaviours.

Gunnel,<sup>1</sup> aged 82 at the time, was a home care user living alone in her house in a small town in southern Sweden. Aligning with principles for ageing-in-place, the Swedish Social Services Act formally allows Gunnel to use care services according to her daily routines. Yet, she rises before 8 AM, contrary to her preference to sleep longer:

Gunnel: I'd have gotten out of bet a lot later, but this is how it is.

Interviewer: I see. Why is that?

Gunnel: Well, they have... I have never talked to them about it, actually, but I thought, well, it's perhaps part of their schedule to come for their visits at between 8 and 9 AM. Yeah, I don't know... maybe they could... no, it's good like this, actually. <..> I feel I want to fit into their schedule, now that I belong to them. Yes.

By "they" and "them" Gunnel referred to care staff. As the interview unfolded, Gunnel gave several illustrations to how her life was influenced by home care provision: meals, sleeping patterns, social life, and the character of her home, had all become aligned with its logic. Other respondents gave similar accounts. This article investigates how the provision of home care may have an institutionalising impact, drawing on Goffman (1961) and building on Golant (2015). It shapes users' everyday life in a way that in certain aspects resembles moving to a residential care unit, but without actually leaving home. While fixed routines may contribute positively to the quality of life for some, providing a sense of predictability and safety, this impact can also erode care users' independence, thus challenging the original purpose of domiciliary care.

As a welfare concept, home care in Sweden was launched in the early 1950s, following critique against previously existing nursing houses. Swedish care homes of older times constituted the dominant form of the country's eldercare up until the late 1940s and would likely have earned their place among Goffman's "total institutions," had he studied them. Their institutionalising character was highlighted by renowned author Ivar Lo-Johansson, accompanied by photographer Sven Järlås, mobilised into activism by a radical seniors' organisation. They visited nursing homes and published books, successfully voicing their criticism within the public debate (Gaunt, 1995). In *Ålderdom* (1949),<sup>2</sup> Lo-Johansson criticises "the undifferentiated mass of sameness in the nursing home" (p. 26) and describes how the care homes violate older people's individualism

<sup>&</sup>lt;sup>1</sup> This name is fictious, as are all respondents' name in this article.

<sup>&</sup>lt;sup>2</sup> Published by the journal "Vi."

and identity. As a result, eldercare institutions were scrapped as the state's core strategy, and home care was introduced instead.

Early-days home care was provided by part-time working so-called *Samaritans* who enjoyed a high degree of discretion. As the sector swelled, home care provision was scaled up, including staff unionising, full-time working norm, guidelines, and, finally, educational requirements (Szebehely, 1995). Administrative power was transferred to the 290 local municipalities. Following the neoliberal turn of the early 1990s characterised by market logic and New Public Management, and austerity measures in the wake of a financial collapse in the subsequent period, home care was restructured according to an assembly-line logic still in reign today. And towards the end of the 1990s, a cost-centred aging-in-place-policy led to the closure of tens of thousands of places in the remaining nursing homes, while parallelly the number of people aged 90 and over increased. This development resulted in more stringent qualification requirements for those wishing to relocate to care homes, meaning that a larger number of care users with severe disabilities had to remain in place using home care (Peterson & Brodin, 2022). One effect of the combination of these factors is that many care users experience multiple staff visits per day. The average user meets 16 different staff members within a fortnight.<sup>3</sup>

Swedish domiciliary care touches the lives of a significant proportion of the older population. Approximately 232 000 individuals aged 65 or more were registered as home care users by October 2021; 16 per cent of all people aged 65 or more use one or more services from the social care sector (Socialstyrelsen, 2022). Home care is formally authorised by the Municipal Social Services Administration for those found eligible after a needs assessment. Support is provided in accordance with the Social Services Act, delegating municipalities the responsibility for older persons' well-being, emphasising the duty to enable them to live independently and, as far as possible, "choose when and how support and assistance in the residence and other readily accessible services are provided."<sup>4</sup> The assessment process considers the applicant's own abilities and support needs. For people on a low income, services are free of charge and there's a cap on the monthly fee, meaning that no home care user pays more than about 200 euros per month, regardless of the extent of the services.<sup>5</sup> Home care commonly includes assistance with meals, personal care, purchases, house cleaning, laundry, and medication. The interviewee Gunnel was, in this respect, a fairly typical home care user (and is therefore quite visible in this article): she needed help with medication routines, meal preparation, groceries, and house tending, whereas she was still able to manage her personal care including intimate hygiene.

Despite its relatively high outreach and importance for many, contemporary home care is increasingly described using negative connotations: high staff turnover, high stress levels, and minute-timed detailed care visit schedules that deprive staff of discre-

<sup>&</sup>lt;sup>3</sup> https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2023-3-8444.pdf

<sup>&</sup>lt;sup>4</sup> https://www.riksdagen.se/sv/dokument-och-lagar/dokument/svensk-forfattningssamling/socialtjanst-

lag-2001453\_sfs-2001-453/, 5:5§

<sup>&</sup>lt;sup>5</sup> The lion's share is covered by taxes.

tion. Users and staff alike repeatedly complain about stress and time constraints (Ernsth Bravell et al., 2021; Strandell, 2023). There's a widespread media usage of terms related to crisis and problems (Akademikerförbundet SSR/Kommunal, 2013; Szebehely et al., 2017). In an international comparison, however, the coverage is still high, and home care does ease thousands of family members off care duties which would otherwise stress mainly daughters and partners of older people in need of support. Services are provided at a heavily subsidised price, making them accessible for all. Surveys – albeit disputed – repeatedly show that most home care users are satisfied with the care provided.<sup>6</sup> As home care constitutes a cornerstone in Swedish welfare, framed as an emancipatory tool for older people's independence and promoted as an example for other countries as well, academic interest is motivated.

International research, conceptualising home care as different from nursing homes, associates the latter with institutions in an unfavourable sense. Öhlander (1996) analvsed group homes in Swedish dementia care from the perspective of Goffman's total institutions, finding numerous similarities. In a life-story interview study, Charenkova (2023) saw that Lithuanian care users' views on nursing homes carried primarily negative connotations, linked to generally negative associations with such institutions; Grabowski (2022) argues that US nursing homes should be improved to be more "home-like" (p. 4). Malmedal (2014) explicitly claims that Norwegian nursing homes to some extent deserve the label total institutions. Other works more directly contrast residential nursing, linked to depersonalising institutionalisation, against allegedly emancipatory-oriented home care. de Medeiros, Carletti et al. (2020) found in a scoping review that older people living in nursing homes thus "considered institutionalized" (p. 4) experience a lower quality of life than those using home care. de Almeida Mello, Declercq et al. (2016) juxtaposition home care to residential nursing, advocating the former as a way of delaying the individual's move into a residential care which entails the risk for "depression, loneliness, decreased quality of life, increased use of medication, and greater mortality" (p. 2251).

Building on such criticism, Rogers, Ramadhani et al. (2020) promote ageing at home defining that as a journey "to maintain independence in one's place of residence" (p. 9). They put forward a widening concept building on ageing-in-place intending to sustain care users' independence while acknowledging that moving into a more convenient setting as support needs change may enable ageing in the "right place" (p. 9). The authors refer to Bigby (2008) who associates ageing-in-place with staying in "familiar surroundings, close to family and friends, to retain personal belongings, and avoid institutionalisation" (p. 77).

Challenging this home care/care home dichotomy, the present article explores contemporary Swedish home care as an arena where a subtler form of the individuality-eroding process instead takes place at home, and the home gradually assumes the character of the total institution. The aim of this article is to elucidate an institutionalising logic that influences home care users, basing the results and conclusions upon home care users' experience.

<sup>&</sup>lt;sup>6</sup> https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2023-10-8759.pdf

### Theory

The concept of total institutions in modern society has been revisited over the decades, following Goffman (1961) and Foucault (1977), focusing on the disciplinary intentions within institutional handling of humans, and Townsend (2023), who visited eldercare units and criticised the erosion on residents' individuality, suggesting the development of comprehensive home care. While Goffman and Townsend examined micro-level circumstances, Foucault shed light on their macro-scale manifestations. Referring to both Goffman and Townsend, Reed-Berendt (2022) discusses institutionalisation, finding that

'decisions', 'responsibility', 'choice' and 'control' are fundamental to human flourishing, and that environments that deplete these opportunities are harmful, corroding the self (2022) (p. 108).

The author refers to an experiment carried out by Langer and Rodin (1976), finding that residents who were encouraged to assume responsibility for micro-choices, such as what movie to watch or how to decorate their rooms, showed increased well-being within weeks, compared to a control group deprived of this liberty. The present study draws on Hacking (2004) in an attempt to bridge the micro/macro gap and acknowl-edge the importance of the subtler side of how institutional logic influences day-to-day life. The total institution has hitherto primarily been understood as a specific physical and spatial entity, distinguished by supervising and controlling functions. In this article, however, it's the institutionalising logic rather than the site that is explored. By adopting applicable components of Goffman's theory to explore the experience of older people using home care services in Sweden, it contributes to existing research by shedding light on how the logic of "total institutions" can function regardless of physical boundaries such as the solid walls of a prison or a boarding school, and instead exercise an influence on people living formally independent lives in their own place.

Without explicitly connecting to Goffman's concept, some scholars have touched upon how home care provision may dominate care users' life. Wikström (2005) demonstrates the control exerted by care organisations over the scheduling of care visits, finding that minute-scheduled care provision outweighs care users' temporal preferences. This experience is shared by three out of four Swedish care users. Also interviewing users in Sweden, Jarling, Rydström et al. (2018) identified a feeling of "becoming a guest in your own home" (p. 4). Another exploration was undertaken by Ceci (2008), who found that Canadian home care often addresses only a limited range of recognised needs of the care users, thus limiting its ability to uphold care users' individual lifestyle. Dyck, Kontos et al. (2005) highlight how older Canadians' homes are reconstructed as caregiving spaces, arguing that extensive cost-cutting in public care leads to a reduction in services and stricter limitations on care provision. When homes become sites for longterm health care, their primary meanings are challenged.

Glasdam, Praestegaard et al. (2013) studied an older Danish couple's everyday life, focusing on their dependence on health-care staff. Interviewees felt restricted by the

minute-scheduled times and tasks of professionals, likening their situation to a form of imprisonment. The temporal standardisation of home care can, the authors argue, sometimes compromise the independence of older people. This may force them to adjust their lives to the schedules of the professionals, causing a feeling of confinement. One of the respondents described his experience of care usage as "living in Hell" (p. 89). And Golant (2015) observes that support provision in the United States may turn homes "into mini-nursing homes with their institutional- and medical-like qualities" (p. 240), mentioning both temporal and physical features that dominate the care user's life. Golant also shows that older care users who move into assisted living facilities express a desire to have influence on the meal experience and not be exposed to "lukewarm processed dinners" (p. 444), be enabled to pursue personal interests, and prefer their home to be home-like and not "resemble institutional settings" (p. 444). Discussing the transformation of power over people with intellectual disabilities, Altermark (2016) draws on postcolonial theory, particularly the works of Gayatri Spivak, to highlight how historical narratives can serve to obscure continued inequalities and power imbalances. Altermark suggests that while the institutions may have physically disappeared, their logics persist in modern practices and policies that still restrict the lives of people with intellectual disabilities under the guise of promoting citizenship and independence.

The present study builds on these works and adopts an approach drawing on Goffman's total institution to analyse contemporary Swedish home care. To convey this concept, irrelevant or inapplicable aspects in Goffman's concept, such as the physical appearance of the institution or the intentional degradation of inmates for disciplinary purposes, have been excluded. Other core elements were used to identify four aspects of life in the total institution. Those four aspects comprise part of the process of the inmate's death as an individual person that Goffman labels "mortification" (Goffman, 1961, p. 16). They resemble what Hacking (2004) distils (p. 293) and what Townsend (2023) and Langer and Rodin (1976) discovered concerning everyday micro-choices. The categorisation for the current study was established through a reading of Goffman specifically aimed at operationalising the concept of total institutions as an analytic tool for contemporary home care. It can be described as an "enactment" of Hacking's analysis of the total institution, a way of seeing how it is put to work in home care. This approach aligns with Braun and Clarke's "theory-driven" (2006, p. 18) thematic analysis, which involves identifying categories based on a broad exploration of the data set and grouping accounts into categories, informed by a specific theoretical framework. The following are the categories identified in Goffman's essays and an interpretation of their respective characteristics.

*Meal dynamics:* Culinary restrictions are copious for the institution's inhabitants. Nutritional, gastronomical or social aspects of food are regulated by the regime; residents develop strategies for coping with it, such as finding ways to enrich, spice up, or alter the menu and the circumstances around it. In this article, "meal dynamics" entail all of the above.

Daily rhythmics: Residents' circadian rhythms are resolutely impacted by the institution. All phases of everyday life are scheduled and timed according to a logic defined by the management. The regime covers "essential needs" (Goffman 1961, p. 10), including sleeping patterns, meal times, work schedules, and leisure time. This category encompasses the temporal circumstances surrounding all everyday needs and habits.

*Lifestyle realm:* Upon intake, hobbies, pastimes, and personal interests the individual has had prior to institutionalisation are decisively limited. Restrictions also apply to clothes, jewellery, make-up and other attribute regarding appearance. Social interactions are likewise constrained; the individual may rarely meet other humans than staff members and fellow inhabitants. The category refers to all the terms above insofar they conflict with the home care provision.

*Home-space arrangements:* Understood as one physical entity, the institution has traits such as size and layout that do not easily translate to the atomic character of individual care users' homes. Interiorly, however, the institution's physical appearance is defined by the organisation's needs. Spaces have clear intentions. Function prevails over such things as homely vibe and coziness. This more tangible category focuses on institutionalisation of home as a place.

### Method

Those four categories were employed in the analysis of the empirical data. The research data for the current article was gathered within two closely related research projects, "Home care as integrated in older people's lives" and "Navigators of the support system," involving Swedish home care service users (Harnett et al., 2023). The design follows principles formulated by Bradshaw, Atkinson et al. (2017) emphasising qualitative research as a means to explore and comprehend. The empirical material consists of 34 qualitative interviews with 41 care users in southern Sweden, and 15 care visit observations. Interviews, conducted from 2021 to 2023 in participants' homes, involved 26 women and 15 men aged 68–96 living in diverse settings, in both urban and rural areas. Among the respondents were retired manual workers, farmers, academics, and business owners. Four were born outside Sweden. A majority lived alone, though in five cases, a cohabitant assisted in or gave the interview.

Respondent recruitment was enabled partly through collaboration with home care providers in three municipalities, including a pilot study contributing to the actual project. Additional engagement was achieved via media, social media, and our department's website advertisements, attracting participants to indicate interest. An interview guide was created using a methodology aligning with Lesser, Nienhuis et al. (2023). The questions covered home care experiences, such as:

- Can you tell me a bit about what a typical day looks like for you with the home care service? Maybe you can share some experiences from recent times.
- Can you share how long you've been using home care services and how you decided to apply for help at home?
- What kind of help do you get from the home care service?

The interviews and observations were carried out in the respondents' homes. In order to encourage interviewees to share their experiences, follow-up questions were posed when suitable. Interviews lasted 30–120 minutes and were transcribed verbatim. Additionally, coherent texts were created from the observation field notes. For this article, the data was scrutinised for reasoning around the four aspects of everyday life described in the theory section, constituting the themes used to categorise findings in NVivo 1.7.1 software, using theory-driven thematic analysis as advocated by Braun and Clarke (2006).<sup>7</sup> We discussed the preliminary results internally and with stakeholder panels, including care users and pensioner organisations, to receive feedback and reflect on our findings. One challenge encountered during the interviews was that respondents did not adopt to analytical terms formulated by the research team. When, for example, asked about whether interviewees had adopted a specific vocabulary in order to facilitate communication with staff, few responded affirmatively; the overall impression would still confirm that they tend to do so. This poses both ethical and epistemological questions if the findings are found to merit an article on the topic of adaptations.

Analysing data, four readings were performed – one for each category found in Table 1. Every mentioning of events and situations that was possible to connect to the category in question was marked, until each category was saturated with a variety of examples of care users' experiences. Out of the thus highlighted excerpts of interviews and observations, an illustrative sample was selected for this article.

The research was approved by the Swedish Ethic Review Authority (Dnr 2022-00829-02), and participants were orally and in writing informed about study aims and withdrawal rights. Observations emphasised participant consent, with ongoing discussions to determine observation focus. An independent conversation counsellor was appointed to provide support for respondents, should they feel the need for it.

### Limitations

This study uses qualitative data from a small number of respondents, residing in one part of Sweden. Its implications for other circumstances, such as other care regimes and geographical areas, are restricted. In home care environments, or other human service terrains, which are not set up according to an assembly-line, large-scale, market oriented logic, service users' experiences likely differ from what is reported here.

### Results

The empirical data in this research was analysed using the categories described above, resulting in an extensive set of accounts. Here, excerpts are presented to provide insight into users' everyday life and to elucidate the institutionalising logic. Table 1 exemplifies the findings in each of the categories created, describing how an individual care user experiences the logic.

<sup>&</sup>lt;sup>7</sup> More specifically their theory-driven category – see theory section.

Respondent Gunnel, quoted in the introduction, was an typical medium-level care user. She offered numerous illustrations of her experience and contributes strongly to this article. This is motivated partly by her typicality, partly by the fact that, unlike other respondents, Gunnel was generally satisfied with the services, hence did not strive to criticise the care provider.

Meals dynamics	Daily rhythmics	Lifestyle realm	Home-space
Resigns to microwave heated meals	Gets out of bed earlier than desired	Gives up cultivating plants	Gives up certain rooms to staff
Switches to instant coffee or fried eggs	Goes to bed earlier than desired	Gives up gardening	Arranges home to fit staff's needs
Eats alone	Waiting for staff arriv- ing late	Quits going to the movies	Installs nursing bed for staff's convenience
Restricts their menu to fit the organisation's abilities	Preparing service provision to save time for staff	Abstains from shop- ping & going to cafes	Adopts sink heights, thresholds, passages, etc
	Using shower and bathroom when staff is available	Ceases to see friends & relatives	Removes furniture to facilitate work
		Dresses up for staff's visits	

Table 1

## Meal dynamics

Food intake is often influenced by the home care organisation's logic and involves everything from grocery shopping to meals preparation and serving. Users that need meal support often keep a stack of frozen precooked supermarket dishes, to be microwave heated by visiting staff. Staff visits are tightly minute-timed and have no room for actual cooking.

At the day of the researcher's visit for an observation of lunch preparation, Gunnel's meal consisted of a frozen quiche. When presented to Gunnel, who was seated in her living room, a scent of warm cheese accompanied the plate:

Beside the pie, there's one or two tomatoes cut into pieces and a fork. Nothing else comes with the meal. No salt, spices, napkin, or any other extras are provided, and Gunnel doesn't ask for any of it either. (observation excerpt)

In the ensuing interview, Gunnel commented on the sliced tomato, stating that it's "so appealing" when staff takes such initiative since it is not expected. Gunnel makes sure to always keep fresh vegetables in her fridge in case staff would find the extra time to include it in the meal, as happened at this occasion. Other than that, she described the process that day as fully normal, one of many identical lunches. Asked from where she obtains her food products, Gunnel explained that she uses a grocery delivery service,

assigned by the municipal care organisation. Via an online application, she orders the products, assisted by staff if necessary.

The tight, minute-timed care visit scheme is frequently mentioned as an obstacle to obtaining the meals preferred. Gunnel explained that she came up with the idea of replacing her usual boiled egg for the evening meal with a fried one, since staff had told her they were given only seven minutes for that visit:

Yeah, exactly. It's just like that, it doesn't really matter to me if I get my egg fried or boiled, no. <..> Yes, but, since then I've just thought that, rather have, to have something that can be prepared quickly. Yes.

Other users described similar adaptions. Betty, who portrayed herself as a "coffeejunkie" and stated that she loves the Arabic-style cardamom version, had to do with instant coffee, since that's the only type that staff's schedule permits. She claimed it's been years since she had had her preferred coffee. She also lamented the fact that she can never have oven-baked meals, since that it far too time-consuming for staff; a fate she shares with many respondents, who rarely have access to hot meals, unless they have passed through both the freezer and the microwave oven. Falke pitied care users that have no other option than the ready meals from the supermarket:

<..>...these are like those meal boxes you get from the <name of a grocery delivery service> or something... <..> ...and then you just shove them in the microwave. <..> I feel sorry for those who get that kind of food.

Apart from the ingredients and mode of preparation, the meal dynamics entail situational aspects of eating. Interviewees asserted that they usually dine alone, unless they live with a spouse, and some highlighted that the pace and rhythm of eating can be influenced by staff's schedule. For care users that lack the ability to prepare their own meals, alternative solutions are a question of available resources. Gunborg, who can't prepare her own dinners, switched from pricey restaurant food to supermarket meals and said she's satisfied with that:

Gunborg: I mostly eat these ready-made, frozen meals. <..> In the beginning, I had meals, like, home care services would pick up food for me from a restaurant, but that got too expensive over time, so I had to give that up.

In summary, home care meal dynamics limit care users' menu, choice of ingredients, and modes of preparation. The restrictions are motivated by various factors such as staff's tight schedules and the centralised purchasing routine and food delivery system; however, these restrictions are not always clearly articulated or even decided by the care organisation, but can also be self-imposed by care users.

#### **Daily rhythmics**

Gunnel's statement in the introduction about waking up in time was mirrored by other respondents. Few users set the alarm in order to wake up in time for care staff's morning

visit, but many reported adjusting the start of their day to staff's schedule. Betty said she gets woken up by a phone call prior to the first visit:

Betty: They call and wake me up, then I've got fifteen minutes. <..> And if they come too early, they gotta wait downstairs.

Interviewer: But who decides that you should get up exactly at that time? Betty: Well, it's like, it's been decided before, you know, we have someone I call Queen <Name of manager> who decides on, on times and stuff.

The interview guide contained a question regarding adjustments. Several interviewees stated, replying to the direct question, that they had not made any adaptations to the home care organisation's schedule, but when detailing their daily rhythmics gave illustrations to such adjustments. Falke described the temporal logic in terms of "pressure":

Falke: I always have to be mindful, thinking about when they'll come, and then I have to adjust accordingly. So, I live under a kind of pressure, you could say. But it works out. <..> but I have to prepare certain things so that I need to always be a bit ahead of time to meet them.

Mentionings of adaptations – though not always using the term per se – regarding the schedule for eating, sleeping, having a shower, or even using the bathroom, were frequent in the data. The typical home care day seemingly starts at around 8 AM for care users who need help in the morning, and ends relatively early at night, for those who use support at bedtime. Those that reflect upon their situation make the connection between their own experiences and staff's schedule. Anita said:

Anita: It's about the staff's meal times, I've figured out. But, yeah, sometimes I've tried and sometimes it worked, but mostly it goes back to the old anyway. <..> And I think, like I said, it's about the staff's meal times.

Respondent provided plentiful illustrations to how their daily rhythmics were influenced, or even defined, by the home care organisation's schedule. At many instances, their statements regarded both the temporal aspects of everyday life as such, and the opportunities they see within its framework for other engagement. In this, there is a certain overlap with the next category.

## Lifestyle realm

This broader aspect of institutional logics encompasses elements that shape individual lifestyle and identity, such as hobbies, interests, appearance, and community engagement. Respondents claim that necessary support is not offered, even when the needs are quite modest. Several interviewees had had, for example, to give up plant cultivation. Anette said she had been declined help to have her flowerpots watered, referring to how staff had to work according to a vehicle industry's assembly-line logic, which does not permit doing anything out of the scheme:

Anette: I've got three potted plants, but I'm not allowed to have them watered, you know. <..> You know, schedules are made for, like, Volvo Trucks manufacturing,<sup>8</sup> and watering plants isn't included.

And Gunborg found it "unthinkable" to get admission to help with replanting her flowers. Other important aspects of the lifestyle realm, like hobbies and community engagement, take place outside of home. Therefore, support related to moveability such as escort and transportation services is vital to help care users uphold interests and hobbies but is often not provided. Gunborg said she had been forced to quit going to the cinema, but could still go to the forest at times, thanks to help from outside of the home care system:

Gunborg: No, no, I've given up on movies, because it's too much of a hassle. No, I can't continue with anything I'm interested in, except with the help of the transportation service, then I can get out into the woods. <..> Or we take the transportation service to the beech forest <..> ...so that's the only way I can get out of this prison here, because I feel like I'm in a prison. <..> ... home care makes sure the ongoing, the necessary, basic stuff works. But they can't help me with nature experiences or social contacts out in the community and stuff like that.

Betty, whose moveability is severely restricted, had been admitted help from escorting staff enabling her to sustain a personal interest: going to the local record store to listen to music, meeting others, and having a coffee and a pastry in the store's café. The store is just a few hundred meters away from her apartment – still, she never went. She felt hindered by an organisational trait. In order to use the help of an escorting staff member, enabling her to reach the store, she'd have to have that staff member around also while in the store, according to local care management's rules, which would feel awkward:

<..> they're not allowed to just leave me somewhere. So the escort has to stick with me the whole time, apparently they have some responsibility, so if I need assistance at <Name of record store>, they have to sit and wait with me there. And how fun is that?

If Betty would stay for more than half an hour at the record store, the waiting time would also breach the time constraint for the escorting staff. Admittance to service from escorting staff is uniformly, across municipalities, timed at one hour per week, and cannot be "saved" from one week to the next: Betty could not go to the record store for four hours once per month.

Moving outside poses obstacles also to other respondents' social engagement. Bror had led a rich social life including going to dance events but was now restricted to playing cards once per week, due to limitations in care provision. He would otherwise play a lot more often, but since he had no one to play with in his home, he needed assistance to reach the club venue where he'd find other players; such assistance appeared impossible to obtain even though he could not remember having had been explicitly denied it.

<sup>&</sup>lt;sup>8</sup> Referring to the assembly-line in industrial production.

Also at home, individual expressions such as clothes and visual appearance may conflict with care provision, indicating a possible subcategory within lifestyle realm: that of visual self. Users as well as cohabiting partners are affected. Ellen explained that she avoids having a shower or walk around lightly dressed in her home since her husband Charles needs frequent support visits and unknown staff members can be expected to show up anytime. She would not like to be "caught" wearing only a bathrobe:

Ellen: It's not so great when they're supposed to be here at nine because Charles needs his medicine, and I'm just coming out of the shower at twenty to nine and they open the door.

Charles: *They do come too early sometimes... <...> ...just as often as late.* 

Ellen: Yes. Yes, they do. <...> Of course, I have to adjust to that time. <...> And, yeah, other times too, obviously, that I, yeah, am available or whatever you call it... Yeah, make sure to be home then and not, not go shopping, not make calls that I need to make, or try not to, yeah, have any scheduled appointments that don't match. <...> Yeah, it's like, it's built into the system.

Towards the end of this statement, Ellen moved on, thematically, from discussing how home care visits affect her shower routines and choice of clothes to reason around how her social life is influenced – involving going outside, making phone calls, or make appointments to see friends.

### **Home-space arrangements**

Care users sometimes experience significant changes to their home environment, necessitated by decreasing mobility or requirements for assistive technology. At Gunnel's place, though, no deliberate modifications had occurred. Yet, she sensed a loss of parts of her home. Since staff started using her kitchen for preparing meals, it ceased belonging to her, according to what she said during an observation. The excerpt begins with Gunnel consenting to have a quiche for lunch. The staff member goes to the kitchen to prepare it, and Gunnel says that they know where to find what they need:

Gunnel: She knows. They've actually taken over the kitchen. <... > I don't really like that things are in such odd places nowadays... I've been quite particular about how I... well, cups and glasses and such and where they should be. So that they were... yes, on the right shelf and all. It's not like that anymore, now it's a bit mixed up. <... > I don't feel at home in it, you could say.

Apart from gradual changes inflicted by staff's day-to-day work, interior modifications can be called for due to declining mobility. Such modifications may increase the home's aura of healthcare facility. Adaptations include removal of barriers such as thresholds and narrow passages, excessive furniture, or lowering kitchen facilities and replacing an original resting place with a medical bed. While intended to simplify everyday life for the care user, the bed arrangement may also be required respecting staff's work environment. Catrin said she acknowledged that factor, while still finding it challenging to accept her home's transformation, including having to split up from her husband at night: Catrin: Yeah, but I get it. I mean, logically, I understand that they need to be careful with their backs and all. Yeah, it just became, just another thing I had to accept.

Similarly, Cecilia recalled how her house underwent a number of changes as her husband's medical condition declined. In their case, some of the arrangements were never put into use, but they still contributed to a change in the feeling of their home. Cecilia said that the home care staff recommended the devices an told her "it's good to have it here so he gets used to it," while at the same time removing rugs and other obstacles.

#### **Discussion and conclusions**

Gunnel, initially described as a typical care user, has helped illustrating how home care use influences her day-to-day living: While formally living independently in her own house as a retiree, she makes sure to get up in time to meet the staff, prepares herself to be presentable, eats mostly microwave food, wears an alarm unit, and senses that she has had to "give up" a part of her home to the organisation, even expressing that she now "belongs to them." Another respondent, Betty, shares Gunnel's experience, and has also had to abstain from exercising her hobby and her social engagement. Since they are both still able to manage many things independently or with help from others, Gunnel and Betty could probably be considered as affected on a "medium" level within the scope of care usage influence. If multiple home care services are carried out with a relatively high frequency in a Swedish care user's home, that care user can expect everyday life to be influenced so that it becomes more similar to what Gunnel and Betty experience, as if they had all actually moved into the same residential care unit. They are subject to an institutionalising logic: their home becomes a "home care home." Home care provision may not qualify for the term "total institution," but there is a logic at work that involves some of its features.

As described by Goffman (1961), various reactions or ways of resisting or coping with this logic occur. Our interviews contain numerous examples of how users found ways of enriching their lives, carving out their own space within the scheduled care provision: creating special bonds with certain staff members to obtain help outside what's formally been admitted; purchasing additional services using private money; calling other persons, such as adult children, to help with extra provisions; or using small tricks to step outside of the imposed arrangements. Most such strategies require access to additional resources. Coping also involves accepting, and sometimes enjoying, the changes. Several respondents expressed satisfaction, even against the backdrop of the quite significant adjustments they had had to make. Previous research, such as Wikström (2005), has identified the existence of the mechanisms at work here, concluding that care users adopt to the limitations embedded in the specific care regime. These limitations are not always explicitly imposed by the care organisation, but contextually assumed by care users. Betty, who had not had her favourite coffee for "years," did not necessarily ask for it either – she "knew" that it would not be realisable. Bror "knew" he would not receive

assistance for going out of the house to play cards with friends. And Gunborg found it "unthinkable" to obtain help to replant her flowers. Jönson et al. (2021) use the concept of "horizons of possibilities" (p. 196) to describe how individuals adjust expectations to what is perceived as obtainable in the given context, hoping for a "reasonable" outcome. Correspondingly, the institutional logic depicted by the respondents in this paper is not always entrenched in explicit norms and regulations, but rather represent internalised barriers grounded in what seems attainable to the user.

Home care users' control over central aspects of life risk erosion and may be replaced by the organisation's logic. An essential difference to the "total institution" is that this logic does not entail any deliberate attempts to discipline care users. Instead, it can be understood as an unintended effect of large-scale care production, assembly-line mode of work, compressed minute-timed schedules, which indicates that the same effects could be observable in other countries using a similar setup as well – as implied by Glasdam et al. (2013) or Golant (2015).

Unlike the uniform existence in a Swedish 1940s care home that Lo-Johansson campaigned against, most Swedish home care users likely lead independent, noninstitutionalised lives in many aspects. What the findings in this study suggest is that individuality and independence face challenges from the institutionalising logic entwined in contemporary home care provision, paradoxically so since home care has been framed specifically as the emancipating, individuality-preserving alternative to residential care. While Gunnel and other care users may find comfort in the structures that have been introduced to their lives, many express critique and dissent, like Falke who says he's under a "pressure" or Gunborg who feels like she's "in a prison." While that term may appear irrelevant as a general description of contemporary Swedish home care, the system perhaps deserves the etiquette "un-total institution," or "home care home." Home care users are not institutionalised in the "inmate" sense, but there is a logic making it drift in that direction. The outset formulated by Rogers et al. (2020), promoting a broader concept of ageing-in-place as reinforcing care users' independence, is undermined when one's place is invaded, if subtly, by an institutionalising force, suggesting that the total institution could be understood not only as a physical entity, but as a logic. Further research could attempt to use the concept for understanding how service users in other environments are influenced by the specifics entailed in the providing regime. Whether school pupils, people living with disabilities, or clients and customers of commercial enterprises are studied, a logic akin to institutionalisation may be observable to various degrees. Insofar public welfare institutions are explored, unintentional individuality-eroding could thereby be highlighted and debated. Attention should be paid, too, to the fact that service users may be satisfied with the routines that start permeating their lives. Although there are respondents in the present study who criticise the restrictions they face, others describe a sense of coherence and comfort, challenging potential nostalgia for previous forms of domiciliary care.

To match the actual experiences of Swedish care users with the proposed concept of ageing in place or the formal stipulations in the Social Services Act, it would be ben-

eficial to enhance users' impact on care provision and reduce the inflexibility of service schedules. Such adjustments may serve to mitigate the risk of the total institution logic adversely impacting the daily lives of those using home care.

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