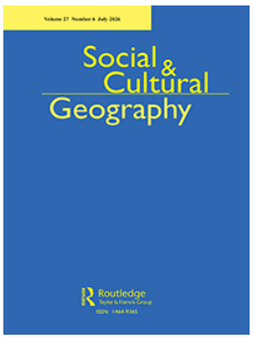

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Caringscapes of Swedish grandparents of disabled grandchildren: informal care in times of refamilialisation

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ABSTRACT

In the context of welfare retrenchment, families in Sweden increasingly absorb responsibilities once carried by the state. This article examines informal care provided by Swedish grandparents of disabled grandchildren. Drawing on semi-structured interviews with 26 grandparents, the study explores how everyday caregiving is organized and shaped by past experiences and future-oriented imaginaries. The analysis combines the caringscape/carescape framework with time geography to demonstrate how constraints and resources at various scales interact to shape informal care. Findings reveal that grandparents' moral responsibilities and lifecourse-acquired capabilities shape their engagement in care and how they structure everyday life around caregiving. Their involvement extends beyond the private sphere into schools, disability organizations and local planning processes, contributing to the identification and challenge of disabling barriers across a range of social environments. The paper advances debates on austerity and shifting cultures of care by offering an intergenerational perspective that challenges assumptions of a primarily nuclear, state-dependent family model in Sweden. It further contributes theoretically and methodologically to social and cultural geography by presenting a transferable visualization of the caringscape/carescape framework, rendering the spatio-temporal organization of care analytically tangible.

Caringscapes des grands-parents suédois dont les petits-enfants sont handicapés : soin informel à l'ère de la refamilialisation

RÉSUMÉ

Dans un cadre de désengagement de l'État-providence, des familles en Suède absorbent de plus en plus les responsabilités autrefois assumées par l'État. Cet article examine le soin informel apporté par les grands-parents suédois dont les petits-enfants sont handicapés. S'appuyant sur des entretiens semi-structurés menés auprès de 26 grands-parents, l'étude explore comment le soin quotidien est

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MOTS CLÉS
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PALABRAS CLAVE
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organisé et façonné par les expériences passées et par des imaginaires tournés vers le futur. L'analyse conjugue le cadre des caringscapes avec la géographie du temps pour démontrer comment les contraintes et les ressources interagissent sur plusieurs échelles pour façonner le soin informel. Les conclusions de l'analyse révèlent que les responsabilités morales des grands-parents ainsi que leurs capacités acquises au cours d'une vie influencent leur engagement dans les activités de soin et comment ils structurent la vie quotidienne pour s'occuper des autres. Leur implication s'étend au-delà de la sphère privée, jusque dans les écoles, les organisationsorganizations du secteur du handicap et les projets de développement locaux, contribuant à repérer et à remettre en cause les barrières rencontrées par les personnes handicapées dans différents environnements sociaux. L'article contribue aux débats sur l'austérité et les cultures changeantes du soin en proposant une perspective intergénérationnelle qui remet en question les présupposés d'un modèle familial majoritairement nucléaire et dépendant de l'État en Suède. Il apporte également une contribution théorique et méthodologique à la géographie sociale et culturelle en présentant une visualisationvisualization transférable du cadre des paysages du soin, ce qui permet de faire de l'organisationorganization spatio-temporelle du soin un objet analytiquement tangible.

Paisajes de cuidado de abuelos suecos de nietos con discapacidad: Cuidado informal en tiempos de refamiliarización.

RESUMEN

En el contexto de la reducción del gasto social, las familias en Suecia asumen cada vez más responsabilidades que antes recaían en el Estado. Este artículo examina el cuidado informal que brindan los abuelos suecos de nietos con discapacidad. A partir de entrevistas semiestructuradas con 26 abuelos, el estudio explora cómo se organiza y moldea el cuidado cotidiano a partir de experiencias pasadas e imaginarios orientados al futuro. El análisis combina el marco del paisaje de cuidado con la geografía del tiempo para demostrar cómo las limitaciones y los recursos a diferentes escalas interactúan para configurar el cuidado informal. Los hallazgos revelan que las responsabilidades morales de los abuelos y las capacidades adquiridas a lo largo de la vida influyen en su participación en el cuidado y en cómo estructuran la vida cotidiana en torno a esta labour. Su participación se extiende más allá del ámbito privado, abarcando escuelas, organizaciones de personas con discapacidad y procesos de planificación local, contribuyendo a la identificación y el abordaje de las barreras discapacitantes en diversos entornos sociales. Este artículo impulsa los debates sobre la austeridad y las cambiantes culturas del cuidado, ofreciendo una perspectiva intergeneracional que cuestiona los supuestos de un modelo familiar principalmente nuclear y dependiente del Estado en Suecia. Además, contribuye teórica y metodológicamente a la geografía social y cultural al presentar una visualización transferible del marco del paisaje del cuidado, haciendo tangible analíticamente la organización espaciotemporal del cuidado.

Introduction

All individuals engage in care relationships at different points across the lifecourse, at times as recipients and at others as providers of care (Bowlby et al., 2010). Within social and cultural geography, care has been examined as a spatially and temporally organized practice embedded in everyday life (Tarrant, 2013) and shaped by lifecourse trajectories (Bowlby et al., 2010). Feminist scholarship has been particularly influential in unsettling naturalized and gendered understandings of caregiving, instead foregrounding care as a political, moral and relational practice (Tronto, 1993). From this perspective, diverse socio-geographical contexts generate distinct cultures of care – including policies, norms and expectations surrounding care provision – across places and welfare regimes (Greenhough et al., 2023).

Sweden, alongside its Nordic neighbours, has long been characterized by extensive welfare provision and a strong reliance on formal care systems (Rauch et al., 2018). However, as in many countries of the Global North, austerity-driven welfare retrenchment has reconfigured the organization of care (Bowlby & McKie, 2019; Power & Hall, 2018). In the UK, Colebrooke et al. (2023) and Macpherson et al. (2023) demonstrate how new cultures of care can emerge following changes in state provision, for example through the expansion of third-sector care organizations and the increasing responsibility placed on individual care recipients. Where formal support fails to meet care needs, family networks often play a compensatory role (Macpherson et al., 2023). In Sweden, welfare cutbacks have resulted in growing difficulties in accessing formal support, even among those legally entitled to it, contributing to processes of refamilialisation that increasingly position families as key sites of care (Rauch et al., 2018). Disability research has shown that disability is experienced not only by disabled individuals themselves but also by family members, particularly parents of disabled children, who often find their everyday lives shaped by disabling societal structures and inadequate support (Landby, 2024; Ljungberg, 2025). While research on Swedish families with disabled children highlights the complexities of organizing everyday life and coordinating support (Landby, 2024), studies adopting an intergenerational family perspective remain limited.

Within the currently shifting care landscapes, older people are frequently represented as recipients rather than providers of care. Yet increasing life expectancy and prolonged good health in later life challenge this assumption, highlighting older adults as significant care providers, not least grandparents caring for grandchildren (Buchanan & Rotkirch, 2018). One subgroup that has attracted growing scholarly attention comprises grandparents of disabled children (Novak-Pavlic et al., 2022). In many contexts, care for disabled children is primarily organized within families (Miller et al., 2012; Moffatt et al., 2019), while Swedish families traditionally have relied on formal support systems. With ongoing welfare retrenchment, grandparents are likely to become increasingly central as informal care providers. Despite this, research on grandparents of disabled children in Nordic contexts remains limited (Novak-Pavlic et al., 2022).

This paper addresses this gap by examining informal caregiving practices among Swedish grandparents of disabled children. It contributes to social and cultural geographies of care by focusing on informal intergenerational caregiving shaped by broader socio-spatial structures, welfare retrenchment and moral norms (Bowlby, 2012; Greenhough et al., 2023; Hall, 2016; Tronto, 2013). Empirically, the analysis

draws on semi-structured interviews with 26 grandparents and addresses three interrelated concerns: how past experiences shape present orientations towards caregiving; how everyday care is organized across time and space; and how future imaginaries inform caring practices.

Conceptually, the paper employs and advances the *caringscape* framework (McKie et al., 2002) to capture the temporalities and spatialities of grandparents' care. While the focus is on grandparents' caring practices and care trajectories, the paper acknowledges that these are embedded within broader *carescapes* shaped by the wider culture of care in Sweden (Bowlby & McKie, 2019). By operationalizing caringscapes as an analytically and visually grounded tool, and integrating insights from time geography, the paper demonstrates how intergenerational care is negotiated across temporal and spatial dimensions.

Although the paper centres on grandparents as caregivers, it does not conceptualize grandchildren as 'dependents' solely by virtue of disability. Instead, it adopts a relational understanding of disability, which suggests that disability emerges through interactions between individuals, environments and support systems. Experiences of disability are thus understood as context-dependent rather than fixed. When using the term 'disabled grandchild', disability is understood through this relational lens (see e.g. Landby, 2024). Caregiving is understood as a practice aimed at easing everyday family life by supporting the family as a whole, particularly during periods marked by intensified parental expectations (Anving et al., 2024) and increasingly curtailed formal support (Rauch et al., 2018).

The remainder of the introduction is organized into three sub-sections. The first outlines the concepts of caringscapes and carescapes alongside the time-geographical framework employed; the second situates care within the Swedish welfare context; and the third presents research on caring for a disabled grandchild. Across these sub-sections, the paper foregrounds informal care, yet situates such practices within the broader carescape. This is followed by a methods section. The results section then presents findings on how past experiences shape perspectives on care and capacities to provide it, the temporal and spatial routines structuring grandparents' caringscapes, and how future-oriented experiences and imaginaries influence caring practices. The paper concludes by situating these findings within debates on changing cultures of care.

Caringscapes, carescape and their time-space specificity

The caringscape framework captures how care unfolds across temporal and spatial dimensions over the lifecourse (Bowlby & McKie, 2019; Bowlby et al., 2010). In everyday contexts, time functions both as a resource and a constraint, shaping opportunities for care provision (Bowlby, 2012). Routines may serve as strategies to support time management, but they can also limit carers' flexibility and time-space freedom (Sihto, 2018). The framework further recognizes that past experiences and future anticipations shape how care is understood and enacted (Bowlby, 2012).

Spatially, the caringscape framework highlights how care is situated in physical and social places at the micro level, such as the home (Bowlby, 2012). However, care may also extend across geographical distance, with family members providing emotional support, coordination and other forms of care without being physically co-present (Bowlby et al., 2010; Hamilton et al., 2022).

Importantly, care is not solely private but embedded within political and institutional contexts (Tronto, 2013). Socio-geographical cultures of care therefore shape how, when, where and by whom care is provided (Bowlby et al., 2010; Greenhough et al., 2023; Tronto, 2013). These macro-level structures are conceptualized as *carescapes* (Bowlby, 2012). The availability and accessibility of formal support condition informal caregiving, and shifts associated with austerity and welfare retrenchment may reconfigure these landscapes of care (Power & Hall, 2018). As public provision becomes more restricted, informal care often gains importance, with family members stepping in to meet unmet needs (Bowlby & McKie, 2019). As Tronto (1993) argues, recognizing unmet needs – often within family relationships – can prompt individuals to take on caring practices. Formal and informal care are thus interlinked, and informal care provided by grandparents may substitute for publicly funded services (Buchanan & Rotkirch, 2018), although such contributions often remain invisible and difficult to measure (Bowlby et al., 2010; Power & Hall, 2018).

Cultures of care within carescapes encompass the moral norms and expectations that shape who provides care and in what ways, and these vary both between and within countries (Bowlby & McKie, 2019; Greenhough et al., 2023). Globally, care continues to be framed as a predominantly feminine responsibility (Bowlby et al., 2010). However, comparative research on caregivers aged 50–75 in Sweden, the UK and Canada shows that gender differences in time spent on care were markedly smaller in Sweden than in the other countries (Stanfors et al., 2019). Although this study examined caregiving broadly rather than focusing specifically on grandparents, it nonetheless highlights the ways in which societal norms shape cultures of care.

Within intergenerational contexts, grandmothers are frequently reported to be more involved in looking after grandchildren compared to grandfathers (Anving et al., 2024; Harrington Meyer & Abdul-Malak, 2020). Yet, drawing on UK data, Tarrant (2013) demonstrates that grandfathers also play active roles in their grandchildren's lives, albeit often through different practices – such as play – which reflect both gendered expectations and continuities with their earlier experiences as fathers. Expectations surrounding parental employment similarly influence whether both parents participate in paid work and how childcare is organized (McKie et al., 2002). Norms governing family practices also inform care moralities, and these can be transmitted across generations while simultaneously shifting in response to broader social change (Hall, 2016; Sihto, 2018).

While carescapes therefore provide the wider structural conditions within which caringscapes unfold, and while macro-level dynamics are acknowledged, the analytical focus of the framework is on individuals' care experiences (Bowlby et al., 2010), which is likewise the focus of the present paper. In this paper, the caringscape/carescape framework is operationalized analytically by combining it with time geography to trace how caring practices are structured across time and space.

Time geography offers tools for analysing how individuals' activities in time – space are shaped by constraints and available resources, traditionally conceptualized as *authority*, *capability* and *coupling* constraints (Hägerstrand, 1970). These refer to institutional and normative structures (authority), individual health and capacity (capability), and the need to coordinate activities with others at specific times and places (coupling). In this study, such constraints are expected to shape grandparents' caring practices. However, these categories may also function as resources: institutional contexts may enable equity and inclusion (authority resources), individual health and caregiving capacity may support

care (capability resources), and intergenerational informal care can operate as a coupling resource. The interaction of these dimensions shapes opportunities in time – space and can produce *pockets of local order*, where constraints and resources are negotiated and routines are established, making everyday life workable. Pockets of local order can be understood as relatively stable arrangements through which everyday activities are coordinated. They are not fixed, but continuously maintained through ongoing adjustments to changing circumstances (Ellegård, 2018). In the context of caregiving, such pockets of local order may enable accommodating care responsibilities alongside other everyday commitments.

Disability care and refamilialization in the Swedish welfare context

The Nordic welfare states, including Sweden, have historically emphasized formalized support systems (Stanfors et al., 2019). Swedish disability policy is anchored in the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), which guarantees assistance for individuals with diagnoses such as intellectual disabilities, autism and physical impairments. Personal assistance, delivered in the home, is a key component designed to promote autonomy and reduce reliance on family members (Rauch et al., 2018). Yet, like many countries in the Global North (Power & Hall, 2018), Sweden has witnessed significant cutbacks in formal support, sharply reducing approval rates for personal assistance, from 70% in 2005 to 17% in 2017 (Rauch et al., 2018). Norberg (2022) argues that this development is shaped by disablism, limiting disabled individuals' opportunities for participation and inclusion on equal terms with their non-disabled peers.

While welfare cutbacks affect all disabled individuals, they are especially restrictive for children and families, given ambiguous distinctions between 'ordinary' and 'extraordinary' parental responsibilities. As a result, assistance is often difficult to obtain even for those who qualify, and Sweden has seen a marked refamilialisation of care (Rauch et al., 2018). In line with this development, disability research has shown that parental responsibilities may extend well into adulthood when formal support systems fail to provide adequate assistance. In some cases, parents continue to co-reside with their adult children with disabilities despite statutory entitlements to support (Ljungberg, 2025). Together, these developments indicate a reconfiguration of cultures of care, where responsibilities are increasingly shifted from formal systems to family networks (Greenhough et al., 2023).

Moreover, norms and expectations play a crucial role in shaping caringscapes. In Sweden, as elsewhere in the Global North (Buchanan & Rotkirch, 2018), grandparents have assumed a more active role in their grandchildren's lives than previous generations (Eldén et al., 2024). Anving et al. (2024) show that grandparents often assist with childcare in response to heightened expectations placed on parents. In Sweden, both parents are expected to work full-time, while contemporary parenting norms meanwhile encourage early pick-up from (pre)school and participation in extracurricular activities. Although grandparental daycare is uncommon due to publicly funded childcare, grandparents frequently ease parental time-space constraints by helping with pickups and accompanying children to activities. Through such practices, grandparents support their adult children in meeting high parental standards, while also being affected by prevailing ideals of 'good

grandparenting' (Anving et al., 2024). Eldén (2026) further suggests that grandparental support in contemporary Sweden can be understood as a form of *sentient engagement*, whereby care is not only practical but also shaped by emotive processes. Grandparents feel a need to be there for their adult children and grandchildren, attending to their needs and taking responsibility for care provision. However, such care is also characterized by ambivalence: while grandparents value these relationships, the expectation to 'be there' can also be experienced as demanding and burdensome.

Caring for a disabled (grand)child

Research in disability studies has highlighted that disability among children often affects family members, as children's lives are closely intertwined with those of their parents and siblings (Landby, 2024). When families encounter disabling barriers or struggle to access adequate formal support, parents frequently assume extensive care responsibilities (Ljungberg, 2025). In contexts of welfare retrenchment, grandparents may therefore become particularly important sources of informal support, helping to alleviate pressures on parents and compensate for gaps in formal provision (Landby, 2026).

Most research on grandparents of disabled children to date derives from non-Nordic contexts, where neo-liberal approaches to care and intergenerational support are more prominent. A recurring theme is how grandparents contribute with time by providing childcare (Novak-Pavlic et al., 2022). Care can be more intensive when a grandchild has a disability, often exceeding that provided for non-disabled grandchildren (Moffatt et al., 2019). Harrington Meyer and Abdul-Malak (2020) found that geographical proximity facilitated caregiving and enabled US grandparents to be active in the everyday lives of their grandchildren, often through routinized practices situated in their own or the grandchildren's homes. Some grandparents even moved closer to be readily available. While grandparents may also provide support across geographical distance, proximity appears particularly important for the regular, hands-on forms of care often associated with supporting a disabled grandchild (Landby, 2026).

Caring for a disabled grandchild may limit engagement in other activities. Moffatt et al. (2019) found that several grandparents reduced work hours or retired early following the birth of a disabled grandchild. However, even when personal aspirations are curtailed, grandparents frequently prioritize family needs (Harrington Meyer & Abdul-Malak, 2020; Miller et al., 2012).

Moreover, research on grandparenting a disabled child consistently shows that caring practices are seldom constant but change over time. Depending on the type of disability, care requirements may be lifelong and increase in intensity, or they may decrease as the grandchild gains greater independence (Moffatt et al., 2019). Circumstances related to the grandparent, the extended family or wider society can also lead to shifts in care provision, for example through changing economic conditions or altered opportunities for alternative forms of support (Harrington Meyer & Abdul-Malak, 2020). By situating grandparents' caring practices within the Swedish welfare context, this study extends debates on how socio-cultural contexts shaping carescapes can affect intergenerational care.

Methods

This paper draws on semi-structured interviews with 26 grandparents of disabled children in Sweden. The study was approved by the Swedish Ethical Review Authority (no. 2024–04230-01). Information about the study and a link for registering interest were distributed through disability organizations and Facebook groups. The inclusion criteria were having at least one disabled grandchild aged 0–18 and living geographically close to the grandchild and their family. Regarding geographical proximity, I did not apply a fixed distance criterion in terms of kilometres. Instead, proximity was defined as living close enough to provide care on a daily or weekly basis. For many, this meant living in the same municipality. The study therefore focuses on grandparents engaged in regular, geographically proximate care and does not capture forms of support provided at a distance.

The sample was relatively heterogeneous, with participants living in various parts of Sweden, mostly urban areas. Twenty were grandmothers and six grandfathers – a common distribution in studies on grandparents of disabled children (see Novak-Pavlic et al., 2022). Ages ranged from 49 to 85, with a mean age of 69; most were in their 60s or 70s, with the youngest and oldest being outliers. Three of the participants were born in other European countries but had lived in Sweden throughout their adult lives. Almost all of the grandparents had a university education and could be considered middle class in the Swedish context. Most were retired at the time of the interview. The sample is thus skewed towards grandparents with sufficient time and financial resources to provide care.

Most grandparents had more than one adult child, while it was common for the disabled grandchild to have siblings and/or cousins. Most grandchildren had either a neuropsychiatric disability (primarily ADHD and/or autism) or a mobility-related disability, with some exceptions (e.g. sensory disability, Down's syndrome). The mean age of the grandchildren was 11. Four children had current access to personal assistance, one had recently been approved but had not yet started, and one was between assistants due to a recent resignation. These children had mobility or sensory disabilities, sometimes in combination. Others fell into disability categories that, according to LSS, could qualify for assistance but had not been approved or had not yet applied. Children with ADHD are not included in LSS, and the additional care required is expected to be provided by family.

Data collection and analysis

Participants could choose between in-person ($n = 15$) or digital interviews ($n = 11$). Consequently, consent was obtained either in written or oral form. An interview guide was used, covering participants' backgrounds, their grandchildren, the care provided (e.g. form and frequency), and experiences of geographical proximity and family relations. Most questions were open-ended (e.g. 'Can you tell me about . . . ?'), and while I followed the guide flexibly, I ensured that all topics were addressed and asked follow-up questions throughout. Interviews lasted between 46 and 112 minutes, averaging 76 minutes.

All interviews were audio recorded (with participants' consent), transcribed verbatim and analysed using thematic analysis, supported by NVivo software. A reflexive approach was employed, with particular attention to the temporal and spatial dimensions of care as conceptualized through the caringscape framework (Bowlby, 2012; McKie et al., 2002). To

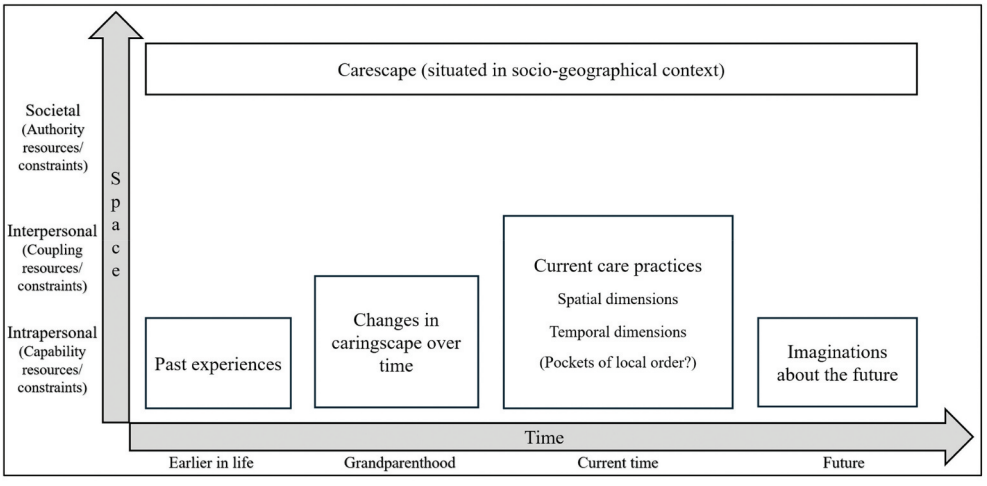

Figure 1. An analytical framework of caringscapes.

operationalize the framework, I developed a visual analytical model (Figure 1), which guided the coding and organization of empirical material into themes reflecting the temporal and spatial dimensions of care.

The analytical framework in Figure 1 presents time along the horizontal axis and space along the vertical. The timescale encompasses previous life experiences, earlier grandparenthood, the present and the future. Its underlying premise is that care practices are shaped by experiences and expectations across the full temporal spectrum. The spatial scale ranges from the intrapersonal (the grandparent), through the interpersonal (extended family), to the societal level, which incorporates socio-geographical context. Time-geographical concepts are mapped onto these levels: capability resources/constraints at the intrapersonal, coupling resources/constraints at the interpersonal and authority resources/constraints at the societal level. All are assumed to shift over time.

Results

The results section is organized into three main sub-sections. The first examines grandparents' past experiences, including family ideologies and work histories. The second, which constitutes the largest part of the results, focuses on their current caringscape (reflecting the central concern of the paper). The third sub-section explores how grandparents' visions of the future shape their caring practices, extending beyond the everyday care of the grandchild.

Past experiences shaping perspectives on care

Individuals' perspectives on informal care, and how these are translated into actual caring practices, are shaped across the lifecourse (Bowlby et al., 2010). In considering how past experiences inform grandparents' current caringscapes, two themes emerged as particularly significant: family relations (Hall, 2016) and work

experiences (Bowlby et al., 2010). Beginning with family relations, many grandparents described being raised with the belief that mutual support within the family is essential:

> You helped each other – that was just obvious when I was growing up. You helped each other with everything. [. . .] We weren't as dependent on support from the state and government as people are today. You had to take responsibility yourself, and I think that helped me in this situation. [. . .] When this happened to [disabled grandchild] . . . it wasn't even a question. It was just, 'we can do this, we help each other, and we can do this'. (Hans)

By viewing intergenerational care as a given, the grandparents partly challenge assumptions about weak extended family ties and strong reliance on formal support systems in Sweden, while also contesting prevailing cultures of care in the Swedish context (see e.g. Greenhough et al., 2023). Perspectives on intergenerational care are also shaped by the time and place of the grandparents' own childhoods (Eldén et al., 2024). Some explained that public childcare was unavailable where they grew up, necessitating the involvement of extended family members. While most participants now lived in urban settings, a rural upbringing may thus have influenced their perspectives. This illustrates how interpersonal relationships and societal structures earlier in life can shape grandparents' motivation to care for a grandchild by contributing to perspectives and moral understandings of the family's role in care reciprocation (Hall, 2016; Tronto, 1993).

Although the role of grandparents has shifted over time, now complementing rather than replacing public childcare (Eldén et al., 2024), caregiving can be more intense when a grandchild has a disability (Miller et al., 2012). In such cases, traditional family values may become more salient. Moreover, while experiences from one's upbringing could differ, it was common that partners had developed a shared morality of care throughout their life together (Hall, 2016) and no major tensions regarding care provision were mentioned, although some of the interviewed grandmothers explained that they provided more care than their male partners. It should also be noted that the sample in this study is likely skewed towards grandparents who are highly engaged and who hold strong views on intergenerational ethics of care (see Tronto, 1993).

Regarding work experiences, the sample was similarly skewed towards those with backgrounds in education or healthcare. Thirteen participants had worked as (pre) school teachers, some in special education, and five had experience in the healthcare sector. This background gave them a pre-understanding of disability and care work, which they found valuable when supporting a disabled grandchild, even though they all lacked experiences of having a disabled family member. Many emphasized that caring for a grandchild was fundamentally different from their professional roles, due to the emotional connection involved. This distinction resonates with the differentiation between *caring for* and *caring about* (Tronto, 1993): while they had cared for others professionally, informal care for a grandchild encompassed both dimensions. Moreover, while moral obligations or societal expectations may shape perspectives that grandparents *should* care for their grandchildren (Bowlby et al., 2010; Eldén, 2026; Tronto, 1993), capability resources mean that they actually *can* (Hägerstrand, 1970).

Care in everyday life

Organization of care provision in everyday time-spaces

To understand grandparents' involvement in the lives of their disabled grandchildren, the frequency of caregiving provides a useful starting point. Most participants reported simultaneously caring for various family members, such as elderly parents or other grandchildren, yet the care provided for the disabled grandchild exceeded other caregiving roles. They commonly described regular and sustained engagement, caring for their grandchildren daily or weekly. This close engagement was shaped by attentiveness to the needs of their adult children, careful negotiation of the boundary between support and interference, and a desire to maintain close relationships with their grandchildren (see also Eldén, 2026).

Spatially, most care practices required time – space couplings between grandparents and their grandchildren (Landby, 2024, 2026). In line with previous research (Harrington Meyer & Abdul-Malak, 2020), most care activities were localized to the home – either the grandparents' or the grandchild's. However, the findings suggest a division based on disability type: grandparents of children with physical disabilities often provided care in the child's home, where necessary equipment was located, whereas those with neurodivergent grandchildren reported more variation. In line with the relational understanding of disability (see Landby, 2024), this illustrates how the spatial organization of grandparents' caringscapes was shaped through the interaction between grandchildren's capabilities, assistive technologies and the material conditions of care, with grandparents adapting arrangements to suit the grandchildren's needs.

Moreover, routines were a prominent feature of the grandparents' caring practices. For many, care provision was planned in advance, with specific afternoons after (pre)school regularly allocated for their grandchildren:

> It has always been that [disabled grandchild] comes to me once a week. And she still does, even though she's about to turn 17. (Åsa)

A few grandparents described more structured and intensive routines than others. While all grandparents lived close enough to provide frequent support, those living in close proximity to their grandchildren (within 1 km) often experienced care as fragmented across the day. Two grandfathers, Stefan and Kent, exemplify such routines, while also challenging gendered norms of care by being among those who provided the most support for their grandchildren:

> My daughter is a preschool teacher and sometimes she has the early shift, starting at 6, and [my son-in-law] always leaves just before 6. When [disabled grandchild] is going to school, she gets picked up by a taxi at 7, so someone has to be there to prepare her. So when my daughter starts work at 6, I'm there. [. . .] It's Monday, Wednesday, and every other Friday. I also have Thursday afternoon, when my son-in-law isn't back from work and my daughter has the late shift . . . then I'm there when [disabled grandchild] comes home from school. (Stefan)

> My day looks like this, on a school day . . . I go to their house at 7 and babysit the kids while [my daughter] accompanies [sister to disabled grandchild] to the school bus. Then [my daughter] returns, and [disabled grandchild] has preschool four days a week, depending on his needs, and I drive him there. [. . .] Then I go back home, and around one o'clock I pick him up – he's there from about half past eight until one, and it benefits him so much that we

> continue with this routine. Then I have a bit of time to do something, and his older sister comes home at either two or three o'clock by school bus, and I babysit again. So my days are highly scheduled, which makes it a bit difficult to do anything outside the home. (Kent)

Kent further explained that while he took on daytime responsibilities such as babysitting and chauffeuring, his wife who was still in paid employment supported the family during the evenings. For these grandparents, geographical proximity enabled short, scheduled care interventions, many of which were pre-arranged and recurrent. Although each instance of care was brief, their frequency implied coupling constraints several times a day (Hägerstrand, 1970) which created spatial limitations. Spatial proximity and routines thus shaped care in various ways: although time – space restrictions were low, flexibility could be constrained by perceived moral obligations to help. This reflects the ambivalence identified by Eldén (2026), whereby grandparents value being available to their families while also experiencing constraints on their own autonomy.

While routines could be stressful for those with the most intensive caring practices, they also helped organize everyday life. These routines enabled grandparents to use tempo-spatial and capability resources to create pockets of local order (Ellegård, 2018), integrating caregiving into daily life in predictable ways despite frequent care demands. In contrast, a few participants did not have any clear routines for care provision, such as Doris and her husband:

> The parents probably want things to be more structured . . . they wanted that from the beginning. But the thing is, we're still quite mobile, for now, so we're active. We have a large social circle and we like to travel, so it's been hard for us. [. . .] Now it's more like, 'Mum or Dad, can you help then?' And we try to rearrange everything so we can. (Doris)

Later in the interview, Doris explained that she sometimes felt 'egoistic' for wanting flexibility, especially as she and her husband were the only ones available to support their adult son and his family. This highlights how the wider carescape (Bowlby, 2012), particularly the lack of alternative care options, can heighten grandparents' perceived responsibility to provide care (Tronto, 1993). Echoing Eldén's (2026) notion of sentient engagement, Doris's account illustrates how being emotionally invested in family wellbeing may generate ambivalent feelings when personal autonomy conflicts with the perceived need to 'be there'. Moreover, the lack of established routines made care demands unpredictable, illustrating how pockets of local order could remain fragile.

Nevertheless, for most grandparents, care provision was rarely either fully routinized or entirely ad hoc. They described a combination where they had regular routines, such as a weekly afternoon, but were also prepared to step in when needed, like Thomas who was 'always on call':

> [My daughter] can call and say like 'What are you doing?' and then we know that she wants help with something and then we just put away whatever we're doing. (Thomas)

This quote illustrates how care was prioritized and integrated into everyday life, often without negotiation or hesitation, even when it challenged the organization of grandparents' pockets of local order. It further demonstrates how pockets of local order

emerged through ongoing negotiation between grandparents' own routines and the needs and schedules of their adult children.

Contributing with time

All disabled children – except the youngest grandchild in the study – attended preschool or school, meaning that most care provision was scheduled during their leisure time. This enabled grandparents to plan other activities during school hours and, for those not yet retired, to combine paid work with caregiving. An exception was that many grandparents were also involved in healthcare-related activities, which further illustrates the temporal and spatial dimensions of care. Tasks such as accompanying grandchildren to medical appointments were typically scheduled during daytime hours, making retired grandparents particularly suited to this role. This supports findings by Anving et al. (2024), which show how full-time parental employment can necessitate grandparental involvement to maintain everyday functionality. Such involvement may be even more pronounced when a grandchild has a disability, given the numerous appointments that typically exceed those of non-disabled children:

> She got quite sick during a period and then I was the one going to the hospital with her. Not when she was hospitalized, but ALL doctor's appointments and so on. It should be me. [. . .] I've been working at the hospital, I was a nurse at the hospital, so she said 'grandpa, you know everyone here'. I guess that comforted her. (Stefan)

Stefan's narrative reveals how his professional background and emotional bond with his grandchild made him the preferred companion for medical visits. This reflects how grandparental care extends beyond practical assistance and involves what Eldén (2026) terms sentient engagement, whereby attentiveness to the needs of family members shapes caring practices. Moreover, such practices reflect the dual orientation of grandparental care – both as a resource for parents and for the child – while also showing how capability resources can be mobilized to decrease coupling constraints between parents and children. The fixed time – space characteristics of healthcare visits made them relatively easy to plan, yet they shaped the organization of the day. Although their schedules were often structured around the grandchild and wider family, many participants were nevertheless able to manage their own activities alongside care. This partly contrasts with previous research suggesting that grandparenting a disabled child is too time-consuming to permit other activities (Harrington Meyer & Abdul-Malak, 2020; Moffatt et al., 2019). Instead, participants demonstrated nuanced time management, often describing that time was their main contribution.

In addition to direct caregiving, some also helped with practical tasks around the house to ease the overall time pressure on parents and allow them to focus on family life:

> Having a house and a garden requires quite much work, and what they are lacking is TIME, since [disabled grandchild] takes so much time. They can't do it all by themselves and would probably have to hire someone to do it, but we do that for them and I think that differs from how it is for other young families. (Susanne)

> I help out quite a lot with everything . . . their cars and everything. They have to be serviced, have their tyres changed and so on. Yeah, things they might not have time for themselves. 'Can you do that, dad?' 'Yes, of course!' (Hans)

While gender differences were not particularly pronounced in the direct care of grandchildren, they became more evident in the broader support provided to the family, such as household maintenance and practical assistance.

Changes over time

Caringscapes typically evolve over time (Bowlby, 2012; McKie et al., 2002). For some grandparents, the introduction of formal support altered their caregiving roles, although few grandchildren had access, reflecting the general decline in allowances for personal assistance and similar provisions in Sweden in recent decades (Rauch et al., 2018). Where grandchildren did receive formal care, grandparents could assume the role of a 'regular grandparent' rather than that of a caregiver. This illustrates how the wider carescape can reshape individual caringscapes (Bowlby & McKie, 2019):

> When the assistants entered the arena, and now he has two assistants 24/7 . . . maybe some night when there's not two . . . it's more that . . . they do the main work. (Birgitta)

However, even grandparents whose grandchildren did not receive formal support experienced changes, mainly that care became less intense and their contributions in terms of time decreased. The main reason was that non-disabled grandchildren grew older and more independent, reducing overall care needs in the family. Changes in caregiving over time illustrate how shifts in various constraints and resources – such as improved authority resources through formal support or increased capability resources of non-disabled siblings – can lead to decreased coupling constraints between grandparents and grandchildren, reshaping both their caringscapes (Bowlby et al., 2010) and the pockets of local order through which everyday care had previously been organized (Ellegård, 2018). Some grandparents of younger grandchildren also saw this as a future possibility, noting that while their caregiving was currently intense, it would likely change over time:

> So you have to be prepared for just about anything. But I believe things change. Life has shown me that it does. It's never the same for many years in a row – after a few years, things look different, I think. (Jannike)

Experiences and imaginations about the future shaping engagement on societal level

When talking about the future, most participants expressed a range of worries. These concerns primarily centred on the kind of support their grandchildren would receive as they grew older:

> Worries are present all the time, how will it go? How will it go for her, later? It's like a huge trauma to think about how it will be and that she will live somewhere where she's taken care of and still gets freedom and stimuli. I find it very difficult to imagine how that will go. (Irene)

> Well . . . I guess what worries me a bit is the struggle that lies ahead. The fight for his rights, you know. That's really what you worry about – how things will turn out in the future. All the support and everything. (Jannike)

Notably, many of these worries were rooted in a perception of society as a place where disabled individuals must continually fight for their rights – even when those rights are legally guaranteed (see also Ljungberg, 2025). These concerns suggest that

grandparents understood their grandchildren's future opportunities as shaped not only by impairment-related support needs, but also by the accessibility of support systems and the disabling barriers they might encounter throughout life. This reflects uncertainties regarding broader landscapes of care, exacerbated by ongoing cutbacks in formal support systems, which not only affect disabled individuals themselves but also ripple across generations. Many participants described themselves as the only consistent source of care, due to insufficient formal support and the absence of other extended family members, which often fuelled worries about their own ageing and health:

> I almost get tearful when I think about it, because it's just us. So . . . but I can say that's one reason we try to stay reasonably healthy, you know. I mean, if we didn't, then that opportunity [to get support] wouldn't exist for them. (Doris)

Grandparents' reflections on the future – shaped by past experiences, current caregiving roles, and imagined trajectories for their grandchildren – often translated into active engagement at a societal level, particularly in domains where formal support was perceived as insufficient or lacking. Grandparents could thus be considered advocates who contributed to navigating and, at times, challenging disabling environments and support systems. While most grandparents recognized the need for stronger formal support, those with professional experience in relevant sectors – such as education or healthcare – were especially likely to pursue change on a broader scale, highlighting the importance of grandparents' capability resources. For instance, grandparents who had previously worked as teachers often channelled their expertise into advocating for improvements in the school environment. Some fought for their grandchildren's right to accessible education, maintaining regular contact with teachers and school leadership to ensure necessary adaptations – particularly for neurodivergent children. As Kristina, grandmother of a child with ADHD and with experience as a preschool teacher, explained: 'I have most of the contact with the school, talking to the teachers'. Some grandparents of children with mobility impairments took action to remove physical barriers in their grandchildren's everyday environments:

> I've fixed a lot for her, like ramps. [. . .] I write in my emails that 'THIS IS AN ACCESSIBILITY PROBLEM', in capital letters and with an exclamation mark, and I think that gets their attention. (Irene)

These examples illustrate how grandparents contributed time and effort to limit disabling barriers and improve both social and physical environments for their grandchildren. Those engaged in improving accessibility – whether through advocacy or practical interventions – often framed their involvement as an opportunity to apply their expertise to secure a more inclusive educational setting, thereby affecting the broader care context around the child. In some cases, this engagement was also driven by the limited time and energy available to parents, prompting grandparents to assume a more active role.

Moreover, many participants expressed strong engagement in disability organizations. While some had been critical of formal support systems and disabling processes prior to becoming grandparents, their commitment to fostering a more inclusive society was often intensified by personal experience. For others, these spaces were new: they became involved in disability organizations after their grandchild's diagnosis, motivated by

a desire to learn more and eventually share knowledge with others in similar situations, as well as with the wider public. Kristina described her involvement:

> Within [disability organisation], I have started a study group for grandparents where we get to meet and talk about like 'what do I experience with my grandchild? What do you experience?'. Giving some advice to each other, trying to find new ways and contribute with knowledge. (Kristina)

Engagement in disability organizations became a way for grandparents to reshape the social and cultural care landscape – not only for their own grandchildren, but for other disabled children as well. This illustrates how multiple temporal and spatial dimensions are intertwined. By mobilizing professional expertise, lived experience, and moral commitment, grandparents contribute to a broader transformation of the carescape. In this way, the caringscape becomes not only a private terrain of support but also a public space of advocacy – where everyday care practices ripple outward to shape more equitable futures (Tronto, 2013).

Concluding discussion

Examining the temporal and spatial dimensions of grandparental care for disabled children in Sweden, this paper contributes to social and cultural geographies of care and foregrounds grandparents as central, yet often overlooked, actors within the contemporary care landscape. The findings demonstrate how feminist geographical approaches that conceptualize care as simultaneously private, moral and political (Bowlby, 2012; Tronto, 2013) can be further developed by attending to informal intergenerational caregiving. By doing so, the paper situates grandparental care within broader moral geographies of family life (Hall, 2016), where responsibilities are negotiated across generations. The findings support a relational understanding of disability (see Landby, 2024), demonstrating how grandparents' involvement emerges through the interplay of impairment-related support needs, disabling barriers and formal support arrangements. These dynamics primarily affect disabled children and their closest family members, but also reverberate across extended family networks as grandparents' caring practices are shaped in relation to their adult children's preferences and needs. The paper thereby extends care and disability research by showing how disabling processes connected to welfare retrenchment (e.g. Norberg, 2022), shape the caring responsibilities of extended family members.

Empirically, the paper demonstrates how refamilialisation is lived and negotiated through situated temporal routines, spatial proximities and moral responsibilities, showing how macro-level transformations associated with welfare retrenchment are translated into everyday caring practices (Power & Hall, 2018). These practices are not merely compensatory, but active reworkings of care that both reflect and reproduce moral geographies of family responsibility. The findings align with Eldén (2026), who argues that grandparental care is not only practical but also grounded in relational closeness, emotional attentiveness, and a perceived responsibility to be there for family members. These sentient engagements may become particularly salient for grandparents of disabled children, as they often navigate the demands of being constantly on call and

emotionally attuned to a family unit facing significant pressure from a retreating welfare state.

Conceptually, the use of the caringscape framework (Bowlby, 2012) illustrates how grandparents' caring practices are embedded in spatio-temporal trajectories that connect past experiences, present routines and future imaginaries, while remaining firmly situated within wider carescapes structured by social norms and policy regimes. Operationalizing caringscapes as an empirically grounded and visually explicit analytical tool enables the spatio-temporal organization of informal care to be rendered visible, thereby offering a methodological contribution to social and cultural geography. By integrating insights from time geography, the analysis further demonstrates how constraints and resources are negotiated in everyday life, allowing grandparents to create pockets of local order within caringscapes (Ellegård, 2018), which are continuously maintained through coordinating care responsibilities, family needs and personal commitments, but may be disrupted by changes in the wider carescape.

Together, the caringscape/carescape framework and time geography foreground how care is shaped through the intersection of intrapersonal, interpersonal and societal dynamics across time and space. Moreover, the findings extend the caringscape/carescape framework by demonstrating that informal caregivers do not merely adapt to existing care structures, but use capability resources to contest and transform them. The framework thus offers both theoretical and policy-relevant insights, contributing to debates on how more equitable and sustainable carescapes might be imagined and enacted.

Building on this conceptualization, Figure 2 synthesizes the empirical findings by illustrating how temporal and spatial dimensions intersect within grandparents' caringscapes. While the figure represents the combined results of the study, it is important to

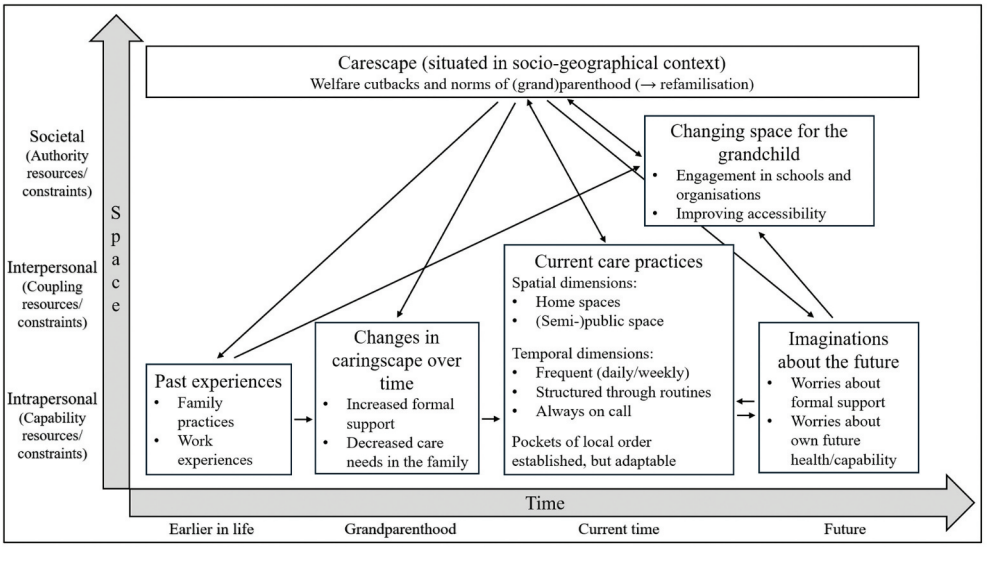

Figure 2. Caringscapes of grandparents of disabled children in Sweden.

note that each grandparent's caringscape remains distinct, shaped by individual biographies, relational configurations and positionalities within the wider carescape.

The caring practices described in this paper largely resemble those identified in previous studies of grandparents of disabled children (Harrington Meyer & Abdul-Malak, 2020; Moffatt et al., 2019), but with a stronger emphasis on auxiliary rather than custodial care. This aligns with patterns of grandparental support in Sweden more generally (Anving et al., 2024; Eldén et al., 2024), albeit at a higher intensity. The relative absence of gendered differences in caregiving may partly reflect Sweden's gender-equal context (Stanfors et al., 2019), though participant self-selection likely also played a role. While the grandfathers in this study provided similar, and at times more intensive, care than the grandmothers involved, some of the grandmothers interviewed had male partners who were less involved. The findings should therefore not be interpreted as evidence of an absence of gender differences, but rather as reflecting the characteristics of the sample.

Austerity and shifting care cultures generate instability in care arrangements (Macpherson et al., 2023), while insufficient formal support may reinforce disabling processes by leaving families to absorb responsibilities that should be collectively secured (Ljungberg, 2025; Norberg, 2022). Reliance on grandparents carries similar risks. Participants stressed that health and energy may limit their future caregiving capacity, underscoring how welfare retrenchment displaces responsibility onto families in ways that may be unsustainable and unequal. Just and stable arrangements therefore require responsibility to rest with formal care systems. A comprehensive understanding of how carescapes shape cultures of care at various scales is essential to ensure sufficient provision (see also Bowlby & McKie, 2019).

Finally, the paper demonstrates the analytical potential of caringscapes as a tool for capturing the complexity of care practices. The approach developed here invites further research into how caringscapes are shaped and experienced across different cultures of care and among diverse groups of individuals. Future studies could examine how changes in carescapes over time reshape individual caringscapes, shifting analytical attention from the individual to the societal level. In addition, examining the experiences of grandparents living at greater geographical distances would deepen understanding of the uneven geographies of intergenerational care. While geographical distance may limit opportunities for regular hands-on caregiving, grandparents can also provide valued forms of emotional, practical and advocacy-based support from afar.

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