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ARTICLE

Co-producing care: roles and strategies of informal carers

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Abstract

The article examines informal carers' experiences of co-producing care, combining notions of carer roles with the strategies used by carers in their interactions and negotiations with the health and social services. The aim is to contribute to the theoretical understanding of carers' role in co-production. On the basis of interviews with carers with a wide range of experiences, we find that they wish to be treated as co-producers, but their roles and impact depend on whether they are tasked with co-producing knowledge or co-producing care. In knowledge production, informal carers are encouraged to take active part and use their voice to further the interests and values of the person in need of support. However, their impact is conditional on their initiatives being recognised by formal caregivers and, to some extent, the person in need of support. In providing care, their efforts largely go unnoticed, and they are less likely to make their voices heard, but their room to manoeuvre appears to be greater. However, when the work of carers is not recognised, formal carers forego resources that are important to the quality and effectiveness of care. The findings, we argue, have important implications for the theory and practice of co-production.

Keywords: co-production; informal care; carer roles; carer strategies; knowledge production

Introduction

As countries reform their long-term care systems in response to population ageing and fiscal constraints, we can discern two major trends: reliance on co-production between service providers and users as an instrument of welfare transition (Flemig and Osborne, 2019; McMullin and Needham, 2018; Organisation for Economic Co-operation and Development [OECD], 2011; Simonsson et al., 2023), and a growing interest in maintaining or bolstering informal care (Loboiko *et al.,* 2025; Verbakel, 2018). Interestingly, the two are rarely explored in context. In a review of the literature, Freijser (2019) finds that informal carers as co-producers are only exceptionally explored, and then primarily in the field of mental health. According to a systematic review, informal carers remain 'invisible experts', neither supported in their own needs nor adequately included in the care for their next-of-kin (Abou Seif et al., 2022). Both in theory and practice, then, the role of carers as co-producers is underexplored.

This paper starts from the observation that both the concept of co-production with carers and the purposes such co-production is to serve is unclear. There is a need, therefore, to unpack the meaning of co-production between formal and informal carers. Against this background, we ask how carers perceive their role(s) vis-à-vis formal carers within the individual service experience and how their experiences can inform theoretical and practical understandings of co-production. Combining recent advances in the theory of co-production (Strokosch and Osborne, 2016; 2021), Twigg and Atkin's models of carers (Twigg, 1989; Twigg and Atkin, 1994) and discussions of carer strategies, we respond to the call for 'further research on the resource implications and constraints for carers (. . .) in their role of facilitating co-production' (Flemig and Osborne, 2019).

Despite heightened interest in the role of informal care in European welfare states (e.g. Courtin et al., 2014; Verbakel, 2018), studies examining the interaction between professionals and carers are often limited to specific patient groups, services or locations. Even aspects that are subject of much research, e.g., carer burden and domains, are commonly considered separately (Loboiko et al., 2023). While attention to the specificity of particular care settings is helpful in developing targeted interventions, it is less useful in developing an understanding of co-production across patient groups, professions and services. Based on the insight that, in countries with comprehensive long-term care systems or comprehensive support systems for informal care, care itself may not be the main source of carer burden (Loboiko et al., 2025), we examine the impact of co-production on carer burden.

The models of interaction, as well as the strategies available to carers, are inevitably coloured by the care regime within which co-production occurs. The long-term care system in Norway, which is characterised by universal services, high coverage and a relatively low threshold for support (Rostgaard et al., 2022), has historically contributed to few intensive carers and a relatively high proportion of less intensive carers (Verbakel, 2018). In the last decades, however, Norway and the other Nordic welfare states have undergone processes of de-universalisation (Szebehely and Meagher, 2018), such as de-institutionalisation, higher thresholds for eligibility and increased attention to the responsibilities of the individual (Zeiner, 2024). Coincidentally, the government has introduced policies and programs that aim to uphold informal care at current levels while relieving the burden of intensive carers (Ministry of Health and Care Services, 2013). Against this background, we argue that, while our results are specific to the Nordic model, they nevertheless provide important insights to other countries, whether they seek to universalise access to resources and services (cf. Spijker et al., 2022) or to reduce carer burden through statutory entitlements to assessment, care and support (cf. Marczak et al., 2022).

The argument is structured as follows: First, we introduce our theoretical framework, followed by a brief presentation of methods and data. In the subsequent sections, we analyse carers' experiences of cooperating with the formal services. The findings are summarised in a final section. We start, however, by introducing the notion of co-production as it pertains to informal care.

Background

By virtue of being parents, children, spouses or siblings, most of us will find ourselves in the role of informal carer at one or more points in our lives. A 2011 survey indicates that, across OECD countries, more than one in ten adults provide help with personal care or basic activities of daily living to family members or friends, and one in three provides help with instrumental activities of daily living (Colombo et al., 2011). However, the extent, nature and intensity of informal care vary between countries and cultural contexts. This variation is associated with family structure and social and cultural values, as well as the quality, scope and form of formal care (Verbakel, 2018).

Scholars have identified a continuum of care regimes, with the ideal types familialistic and de-familialistic on opposite ends (Leitner, 2003; Saraceno, 2010). In the familialistic model, the informal sector is the main provider of care (Twigg and Atkin, 1994). To the formal services, carers are resources – part of the 'taken for granted' reality against which formal services are structured (Twigg, 1989). The role of formal carers is to step in when informal care is not available (Manthorpe et al., 2003). In contrast, in the Nordic, de-familialistic model the superseded carer has, of their own volition or through persuasion, relinquished their role of carer, out of concern for the independence of the user or for the carer themselves, whose well-being and participation in society might be considerably improved by the decision to give up caring (Pickard, 2001; Twigg and Atkin, 1994).

As European governments grapple with population ageing, however, even the Nordic countries have embraced informal care as a means of assisting users – whether old or young – in their preference to stay at home and to contain the costs of long-term care (Alftberg, 2025; Jenhaug, 2018). Recognising that informal care comes at a cost, both at the level of the individual and the state (Rocard and Llena-Nozal, 2022), the challenge for governments is to organise care in ways that allow them to reap the benefits of informal care while minimising the costs. Observers argue that co-production responds to this challenge (OECD, 2011; Pestoff, 2014). The concept, which was coined to capture the contributions to service production of individuals outside the service producing institutions (Ostrom et al., 1978), has spurred two main theoretical traditions (Strokosch and Osborne, 2021): First, co-production as an expansion of the theoretical basis to include the relational aspect of public service production (Osborne, 2010). Second, co-production as an operationalisation of the normative ideal of engaging citizens in service design and production (Jaspers and Steen, 2019). Co-production, in this latter view, is not merely a depiction of the inseparability of service production and consumption but a means of adapting service delivery to tight budgetary and fiscal environments, changing preferences and needs and new and complex social problems (Crosby et al., 2017).

Co-production comes in different trappings and has been defined within different public-sector-reform narratives, such as New Public Management, Public Value, New Public Service and New Public Governance, all of which have been met with criticism (Strokosch and Osborne, 2021). For our purpose, three criticisms are particularly salient: lack of conceptual clarity, failure to address power imbalances and, finally, lack of attention to negative aspects of participation. At issue is the extent to which citizens and professionals are put on an equal footing in co-production, whether opportunities for co-production are equally distributed and whether participation is valuable in and of itself (Strokosch and Osborne, 2021). If these weaknesses are not attended to, co-production 'could go horribly wrong' and might produce deficits in accountability, responsibility, efficiency, equality and equity, democracy and responsiveness, as well as rising transaction costs, inequality and co-destruction (Steen et al., 2018, p. 285).

The article starts from the definition of co-production as 'the voluntary or involuntary involvement of public service users in any of the design, management, delivery and/or evaluation of public services' (Osborne et al., 2016, p. 640) and queries the introduction of the carer into the provider/user dyad. Presently, the role and function of carers as third parties are inadequately explored. For one thing, it is unclear what purposes co-production with carers serves. Are they standing in for the person they care for, or are they participants in their own right? Is the purpose to improve overall services to users, or is it to provide support for their carers? Put simply, the issue is whether and under what conditions informal carers are primarily to be considered co-workers or co-clients (cf. Twigg, 1989). The question is not trivial. In some sense, the notion of co-worker puts the informal carer on par with professional providers, and the notion of co-client puts them on the same footing as the people they care for.

Models of co-producing care

On the basis of the distinction between voluntary/involuntary and conscious/unconscious co-production (Alford, 2016; Osborne et al., 2016), we aim to develop an understanding of co-produced care that considers the extent to which carers are involved in multiple interactions – sometimes over the course of years – with a range of public services. To adequately capture this feature of care, co-production as experienced by carers cannot be treated as isolated or discrete events. Rather, it must be operationalised as a series of interrelated actions and events, occurring at multiple sites and involving a wide array of actors and relationships. Hence, the relationship between formal and informal care is not one but many. We use the co-worker and co-client models introduced by Twigg (1989) to unpack and discuss the concept of co-production with carers. Furthermore, we identify and discuss the strategies used by informal caregivers to navigate and negotiate roles and relationships with the services on the one hand and the person in need of support on the other.

As a co-worker, the carer works alongside the professional in a cooperative and enabling capacity. The carer is brought 'within the orbit of the formal system' (Twigg, 1989, p. 58) and is assigned tasks such as identifying concerns or administering and monitoring the use and side effects of medication (Manthorpe et al., 2003). Hence, the model entails a semi-professionalisation of the relationship between carer and the person in need of care, and the role and status of the carer stem from their expertise, including both their unique and comprehensive knowledge of the person in need of care and the expertise that they have acquired through their interactions with professionals. From the point of view of the services, involving carers as co-workers serves a dual purpose. First, it is a form of user participation by proxy, engaging family or friends to give voice to the needs and interests of users that otherwise lack the capacity for direct participation (Gheduzzi et al., 2021). Second, it is a means to improve the welfare of care recipients while simultaneously relieving increasingly pressured welfare states (Jenhaug, 2018).

As a co-client or secondary client, the informal carer is recognised as needing or deserving help in their own right (Manthorpe et al., 2003; Twigg, 1989), and services are designed to support them in their role as carer. Focusing on the heavy end of caregiving, the services consider the needs and well-being of carers independently of those of the user and attend to their problems even in cases where it might conflict with the needs and interests of the user (Twigg, 1989). Respite care is a case in point. While it relieves informal carers of some burden, allowing them to gather their strength and attend to other interests vital to their well-being, many persons in need of support find it disagreeable (Manthorpe et al., 2003; Pickard and Glendinning, 2001). Such conflicts of interest notwithstanding, many governments have adopted measures directed at carers in the hope that they will contribute to maintaining informal care over time (see discussions in Alftberg, 2025; Loboiko *et al.*, 2025; Marczak et al., 2022; Verbakel et al., 2017).

The models are ideal types, tools of analysis rather than accurate or thick descriptions of reality. To understand how carers relate to and interact with the services, therefore, we must also understand the strategies available to informal carers in their interactions and negotiations with the services. In our material, we identify three such strategies: continuous adjustments, voice and boundary-setting. We combine the notion of carer roles with these strategies to discuss the interplay between formal and informal care and the implications for co-production. Before elaborating, however, we will briefly introduce our data and methods.

Data and methods

The article is based on interviews carried out as part of the project ‘Cooperation between informal caregivers and the health and care services’. Commissioned by the Norwegian Ministry of Health and Care Services, the project examined how health and care services cooperate with carers, how informal and formal carers experience such cooperation, and the effects for carers and services (Gotaas et al. 2020). The project gathered data from different sources, including a survey of Norwegian municipalities and interviews with professional carers. Interviews were conducted during the (COVID) lockdown, a time when healthcare professionals were largely unavailable to researchers. As a result, the data from the healthcare professionals was too limited to be of any real use. In this article, therefore, we report only the findings from our interviews with informal carers.

In autumn 2020, we conducted 12 interviews with informal carers who had volunteered to participate in the study. Two centres for informal carers – in Stavanger and Oslo – assisted us in recruiting informants, and most of the informants in the study contacted us after seeing our call for informants on their respective Facebook pages. We were contacted mostly by mothers, but also fathers, sons and daughters of persons with mental and somatic disorders. However, as none of them were providing care to persons with substance abuse disorders, we reached out to *Ivareta*, an organisation by and for people who are recovering from substance abuse and their families. We also used contacts in our network to recruit persons providing care to older relatives, within or outside long-term care facilities. Of the 12 informants, 8 were women, and 8 were 50 years of age or older. The majority are providing or have provided care for their children, through childhood, adolescence and/or adulthood, but the sample also includes persons providing care for their parents, siblings or partners. A third of the informants care for more than one person.

Given that the informants are self-recruited, they are not representative of the population of carers. In Norway, older persons caring for their spouses, many of whom have dementia, constitute a significant share of carers not represented in our material. Their lack of representation could be a result of our use of digital recruitment channels. Older carers might be less online. They are also less likely to be in contact with carer associations, perhaps because they do not consider their care burden to be heavy enough. Intensive carers, on the other hand, are overrepresented. The majority have provided care for more than a decade, three of them for more than 30 years, and they have interacted with a wide range of health and care services over longer periods of time. Almost all have higher education, which might provide them with the knowledge and skills to articulate needs and make demands (Twigg and Atkin, 1995). Notwithstanding these biases, the strength of our material is that it represents considerable breadth and variation in the type of carer roles, as well as in the services with which they have interacted. Given this variation, the range of common experiences that we identify across carer situations and services is striking.

The research design, including interview guides and procedures for storing and anonymising data, has been evaluated by the Norwegian Agency for Shared Services in Education and Research (SIKT), which included an assessment of our procedures for recruiting informants, as well as of the confidentiality and safe storage of data. All informants were informed that they could withdraw from the study without consequences, and where necessary, their biographies have been slightly altered to prevent identification of informants.

Interviews were semi-structured, varying from approximately one hour to three and a half hours. In general, the interviews had a duration of one and a half to two hours. Due to COVID restrictions, most of the interviews were conducted digitally, but informants who preferred to meet in person were given the opportunity to do so. We asked the informants to recount the main features of their care situation, family situation and experiences with various services, including how the user's needs and their own needs have been attended to. Almost all told us that this was their first experience of telling their history in its entirety, and that they would have appreciated it if the services had asked them to provide such a narrative. All interviews were conducted in Norwegian. We have translated the excerpts used in the article.

The analysis uses an abductive approach. Through a dialogical exchange between theory and data, we examine data from different angles and contribute to theory development. We use a procedural perspective and a narrative approach to identify key dynamics in the interactions between informal and formal caregivers. The interviews provide thick descriptions and point to temporality as a central factor in the relationship between formal and informal care. Through close analysis of the experiences of individual informal caregivers, we seek to identify patterns of general relevance. The remainder of the article is structured as follows: We start by examining the notion of carers as co-clients. We then proceed to discuss their experiences of being or trying to become co-workers, discussing both the knowing and the providing of care. Finally, we conclude with a discussion of the concept and purposes of co-production with informal carers.

Carers as co-clients

It is well known that informal care affects the emotional, physical and financial burdens of informal carers. It comes as no surprise, therefore, that the carers we have spoken to report adverse effects of caregiving on their health and employment status, as well as their relations with other family members and friends. Nevertheless, it bears repeating. In the words of three of our informants:

> Many relatives feel like isolated islands, doing their best to survive (Carer 11).
>
> It is a terribly painful life. Your stomach aches constantly. You are unable to sleep (Carer 5).
>
> I worry for my parents. (. . .) They are confused and (. . .) have poor memory. [Caring] affects their health, both physically and mentally (Carer 2).

Many have found it impossible to continue working as before, either because caring has had detrimental effects on their health or because they have found that their obligations as carers are difficult to combine with full-time work. Some explain that they have been desperate for respite and support. A mother with two severely disabled children recalls breaking down in a meeting with the social services: 'I cried and said, 'you must take him', I cannot take it anymore' (Carer 6). Another mother, juggling the care for her son and that of her ailing older parents, called the municipal services, telling them, 'I cannot take it anymore (. . .) I need help' (Carer 7). Most of them have received some form of support from the health and social services. However, they have mixed feelings about the services they are offered as co-clients. Some tell us that they have asked for respite but have been offered carer allowance or psychological support. Others experience that, while the services provided do give them some form of respite, they are not suited to the needs of the person with support needs. Whether they accept the services or not, their experiences are a reminder that privileging the needs of the carer over those of the user comes with costs to both parties. One informant, who has pressed for her mother to be admitted to a long-term care institution she deems inadequate to her mother's needs, tells us: 'I do not think her life is dignified. [But] I had to make the choice' (Carer 4). Another informant stresses that 'My needs were for the children to be given good treatment, and for me to be given adequate support' (Carer 3).

Only in one respect do carers express a need that is independent of the wellbeing of the person in need of support, namely the need for recognition. Few report that the services have asked them to share their experiences, and even fewer feel that their efforts are recognised. To many, there is a sense that caring puts them apart from their family and friends and that neither their peers nor the services recognise the burden of care. Some find support in meeting others in similar situations, for example, through participation in activities organised by various user organisations, and a few have been offered similar support organised under the auspices of the health and care services.

Above all, however, the carers ask that their knowledge be recognised. While they want and need respite and support, they are not content with being put on par with the persons to whom they provide care. Instead, they ask that they be treated as co-workers and that their contribution to the overall care of the person in need of support is recognised by the formal carers with whom they interact. As we will see, accommodating this wish would entail recognising them both as co-producers of knowledge and as co-producers of care.

The co-production of knowledge

Issues of knowledge are key to carers' understanding of themselves as co-producers. Knowledge, in this context, includes both the knowledge that the carer has of the interests, needs and values of the person in need of support, as well as the expertise they have acquired in the provision of care. This expertise includes, but is not limited to, knowledge about symptoms and side effects of treatment and knowledge about the long-term care system more generally. On the basis of these claims to knowledge, they ask to be recognised as co-workers. In this section, we will consider their claims and discuss why it is sometimes difficult for the services to heed carers' desire to be treated as co-producers of knowledge.

Several of our informants point out that, because of their intimate knowledge of the person in need of care, they are uniquely positioned to represent them and their interests vis-à-vis the services. A man who has provided care for children with disabilities, as well as his parents, and is currently caring for his wife explains:

> We understand their weaknesses and disadvantages, as well as their disease, much better than those who [only] see our loved ones from time to time. We also recognise differences in [their] levels [of functioning]. My mother was hard of hearing and almost blind, and spoke a different dialect, and perhaps agreed and said yes because she did not want to be a bother. She did not understand. It led to some conflicts (Carer 12).

Especially in cases of substance abuse or mental health problems, our informants point out that the patient or user might not be the best source of information. A mother whose son suffers from severe depression tells us that, on bad days, he refuses to meet with health and social care professionals, and on good days, he 'puts on what he calls a mask, is reflective and (. . .) appears to be (. . .) in control. I have brought him to several health and social care agencies, and their conclusion is always that "yes, he is struggling, but he is in control"' (Carer 8). She has spent considerable time and effort convincing professional helpers that her son struggles with activities of daily living, such as managing his money, cleaning and taking care of his hygiene.

Furthermore, carers maintain that they have acquired expertise and experience through their care work, as well as through courses, studies or their professional careers. Several of our informants have themselves worked in the health and social services. Some have received training under the auspices of the healthcare services or user organisations, and others have learned through interactions with the health and social services over years of providing informal care. Finally, some have acquired in-depth knowledge of the workings of the system. Especially in cases where there is great uncertainty associated with both diagnosis and treatment, the carers have spent a lot of time navigating the system, trying to find the right treatment for their family member.

Regardless of how their knowledge has been acquired and what kinds of knowledge they possess, carers often feel that their knowledge and experiences are disregarded. Transitions from care in institutions to care at home appear particularly problematic, and several of our informants recall instances where their input was ignored:

> We got a call that she was to be returned to her home. We were against that. We did not feel she was ready (. . .). But it was done anyway. We were left with responsibility for her during the holidays. The municipality had not arranged any kind of follow-up. They did a home visit and concluded that there was not much they could do, because she did not want help. (. . .) It was strange. When she was to be admitted to hospital, my signature meant a lot; when she was to be discharged, my opinion meant nothing (Carer 4).

When it is recognised, however, this recognition is greatly appreciated. One of our informants explains: 'The trust I have been shown; that I can administer medication, it has meant a lot' (Carer 9).

Why then, if carers want to co-produce knowledge and professionals and policymakers recognise their expertise (e.g. Ministry of Health and Care Services, 2017), do carers nevertheless find it difficult to be heard? In our interviews, three possible explanations stand out. First, the knowledge and opinions of the informal carer as a lay person are not always compatible with professional knowledge and experience. Several of our informants point to instances where their understanding of a situation has been in direct conflict with those of their professional counterparts. A mother whose son sometimes uses illegal substances as self-medication believes that his therapist is wrong in insisting that he should be admitted to a detoxification facility before receiving treatment for his depression. A father whose daughter has been sectioned on several occasions has developed a deep distrust of psychiatry as a profession. If the gulf between the knowledge of the professional and the knowledge of the informal carer becomes too wide, it might prove difficult for the professional to accommodate the point of view of the carer regardless of who is ultimately in the right.

A second objection is that the opinions of the carer and the person receiving care do not always align. A son recounts his father's last weeks:

> The Christmas before he died, he had been hospitalised and wanted to go home. We told [the hospital] that this was a bad idea, we told them he could not go home. But the hospital told us he wanted to go home, and they could not overrule his decision (Carer 10).

Another informant suspects that his brother has not exempted the services treating him from the duty of confidentiality and that they are therefore prevented from involving him in decisions concerning his brother's care. These situations illustrate the limitations of the notion that carers could act as co-producers by proxy. Unless the user is underage or has otherwise been declared to be without legal capacity, it is very difficult for the services to involve informal carers against the will of the service recipient.

Finally, as one informant reminds us, when a family member becomes ill, all carers enter a 'landscape [that] is completely foreign, you do not know the disease and prognosis, what are your rights and obligations' (Carer 12). In this situation, strong emotions are not uncommon. Several of our informants' report being perceived as too emotional, fussy or overly concerned, particularly where the diagnosis of the person in need of care is non-specific or unclear or has a relational aspect. Although they maintain that professional carers should be able to tackle outburst of emotion, they have in different ways and to different degrees had to learn, in the words of one informant, 'what are the relevant arguments, not to shoot from the hip' (Carer 12).

Together, these experiences serve as a reminder that notions of co-production with informal carers, that is, based on voluntary and conscious participation, will always be conditional on the willingness and the ability of the other parties to include them in the process. However, there is a sense in which co-production is an inevitable part of service provision. In this sense, participation need neither be voluntary nor conscious. In the next section, we examine this notion of co-production as 'doing'.

Co-production as 'doing'

The experiences of the carers illustrate an important aspect of the caregiving triad: that care is not primarily 'bought' or 'received' but 'done' by the care recipients and their carers (Mol et al., 2010); they '"quibble", test, touch, adapt, adjust, pay attention to details and change them, until a suitable arrangement (material, emotional, relational) has been reached' (Winance, 2010, p. 111). In other words, working alongside the services is ultimately about doing – providing care and carrying out various administrative and practical tasks, even in the Norwegian de-familialised model. Consequently, the roles and strategies of the carers are complex and shifting, especially where the needs of the person with support needs are extensive and complex. Because they receive assistance from different services at different levels of government, the carers are part of several care triads. In addition to different and changing roles, the carer might be tasked with different duties and tasks in each triad, which, taken together, often add up to a big job. A striking feature of informal care, then, is the complexity in the work and roles of informal carers.

Sometimes the tasks are made explicit, if not coordinated. A mother of two disabled children explains:

> everyone expected us to do [physiotherapy], arrange for a refund of the wheelchair, the school expected us to arrange this and that. It was not much each of them expected of us, but the doctors expected us to order the handrail, everyone expected that a mother does this, or a mother and father do this (Carer 6).

At other times, the tasks result from the unintended consequences of decisions made by others, often without regard to their impact on the carers. One informant describes the consequences when the psychiatric hospital, unable to handle her nephew, discharged him without ensuring that he was followed up with elsewhere: 'he is (. . .) left to his own devices (. . .) the social security benefits do not arrive, and then he ends up back with his grandparents' (Carer 2). More than once, the grandparents or the aunt have had to call for an ambulance and police. As a result, the family is on constant standby, feeling that their life is on hold, waiting for the next crisis. While the concrete challenges our informants face vary, the pattern is familiar. They often feel that they are expected to facilitate and follow up on the interventions of the services, without their own knowledge, experience and needs being heard.

Interestingly, the burden of providing care appears to be higher where the carer senses that their contribution is invisible to the services. In part, this is a matter of unclear expectations. The carers recount operating in an indistinct landscape, with unclear and shifting roles and responsibilities. Knowing what is expected of them and what they can expect from the health and social services could help them navigate:

> Clarity is of utmost importance. That [the services] are very clear about what they can do and what we cannot expect them to do. Clear communication, and especially clarification of the grey areas [between family care and formal care] (Carer 10).

However, directly negotiating their duties and tasks with formal carers is not the preferred option. As one informant points out, because of asymmetries stemming from, among other things, the different status of experiential and professional knowledge and the different obligations emanating from the status of formal versus informal caregiver, the risk is that, rather than relieving them of obligations, such negotiations will bestow more duties on them.

Instead, the carers employ different strategies to find a compromise that is acceptable to them. One such strategy is continuous adjustment. Some carers have developed a sensitivity for how to orient themselves in the system – for when there is something to be gained from further interaction and for what kinds of demands they can make in what situations. A mother whose son consistently rejects all offers of help from the health and social services attributes her success in establishing a team of helpers around her son to her ability to navigate the system: 'I know where to go and how to figure things out, and how to present my case' (Carer 8). The use of narratives is another strategy:

> When we moved (. . .) we were on the lookout for a GP [general practitioner] who would attend to our needs. We wrote a letter. It was originally the idea of my daughter; she had experienced that it was difficult to find a GP that met her needs. ME [myalgic encephalomyelitis] is a problematic disease, where some therapists have strong opinions about right and wrong. When she was looking for a new GP, she gave a short presentation of herself and her needs and said that she hoped she and her potential GP could get to know one another. It proved to be a good start. We decided to do the same because my wife has six to seven different diagnoses (. . .). The GP appreciated it (Carer 12).

A third and final strategy is to set boundaries. Where adequate services are not in place, and the efforts of communicating needs of carers and users fall short, informal carers risk exhausting themselves to no avail. Although to most of our informants giving up is not an option, some nevertheless do. Even though they recognise the costs to themselves as well as to the person in need of care, they accept being superseded by services they regard as insufficient:

> Sometimes I struggle with my decision. (. . .) But I had to make a choice. If I am to retain my health and my relationship with my children and grandchildren, I cannot spend more effort on her care. I have reached a point where I have accepted that things are as they are (Carer 4).

However, decisions to exit come at a great cost. Another carer explains:

> Setting boundaries is a strain. He gets mad at me but also tells me he understands. This is not a way to build relationships. It is a great burden [setting boundaries] (Carer 2).

In contrast to other carers who express discontentment with the workings of the health and social services, the relationship of the superseded carer to the services is not characterised by resentment, but resignation. They recognise that the services see and understand their plight but also that the services are unable to provide the help their family member needs.

To summarise, while providing care is ultimately about ensuring good care, this form of co-production as doing does not necessarily improve service delivery. Rather, it denotes the inevitable but often unarticulated demands that service delivery places on the recipients of care and their next of kin. In this respect, the experiences of our informants are a reminder of the importance of the relational aspects of public service production. If co-production is understood solely in terms of agreed upon interactions between the patient and the formal and informal carers, one loses sight of the continuous adjustments of care practices and day-to-day life made by informal carers. Put simply, when accepting that the contributions of informal carers remain invisible, one also accepts that the specificities of care are rendered invisible to the services and wider society.

Conclusion: Experiences of co-producing care

Through an examination of informal caregivers' experiences across patient groups, relatives, professions and health and welfare services, we have sought to operationalise co-production with informal carers. We find clear convergences of experiences among informal carers – most notably that, even within the service-intensive Nordic welfare context, informal carers are key to service production. However, the nature of co-production is dependent on whether carers are tasked with co-producing knowledge or care. In knowledge production, informal carers are encouraged to take active part and use their voices to further the interests and values of the person in need of support. However, their impact is conditional on their initiatives being recognised by formal carers and, to some extent, the person with care needs. In providing care, their efforts largely go unnoticed, and they are less likely to make their voices heard. Because care is largely provided outside the auspices of the formal services and this doing on the part of the carer is not thematised in meetings with formal carers, their room for manoeuvre is in some respects greater. It should be noted, however, that, even if it might be difficult for formal carers to fully accommodate informal carers, in not accommodating them, formal carers forego resources that are important to the quality and effectiveness of care, i.e., the information, knowledge and work efforts of informal caregivers, and risk creating new clients, thus further straining already strained resources.

These findings have implications for both the theory and practice of co-produced care. Previous studies have shown that informal carers struggle to navigate a fragmented system, pointing to a need for measures and interventions that support and guide informal carers in their interactions with service providers. However, our study sheds light on the extent to which informal care work is invisible both in theory and in practice. Informal care includes tasks that, while essential to good care, are difficult to define and quantify. The invisibility of informal care work can, in part, be ascribed to the asymmetries between formal and informal care. For the study of co-production, therefore, the combination of carer roles and strategies serves to deepen and widen our theoretical understanding of co-production, particularly the distinction between co-production that is active and solicited and co-production that is taken for granted. For policymakers and service providers, the study serves to highlight the extent to which formal services rely on the often unrecognised efforts of carers, as well as the costs to individuals and society when carers are no longer able to contribute to the care of their family members. To establish adequate measures and interventions, therefore, sufficient time and resources should be set aside for dialogue between formal and informal carers, ensuring that the continuous adjustment and other coordination tasks of informal carers are rendered visible and recognised by formal carers and policy makers.

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