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Co-production in coping with care dependency in Germany: How can integrated local care centres contribute?

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Abstract

In Germany, most care dependent people are looked after by family members at home. Professional support can help ease the burden of caring relatives and stabilise home care. Ideally, care then is provided through the co-production of formal and informal caregivers. This article analyses how care dependent people and their family caregivers integrate professional support into their care arrangements. An analysis was conducted using data collected for a qualitative study evaluating integrated local care centres in North-Rhine-Westphalia, Germany. The study is based on episodic interviews with users of these care centres and their family caregivers ($N = 26$). During the analysis, three interpretive and practice patterns relating to co-production of care were identified. These patterns reveal how the interviewees deal with (increasing) needs for assistance and care while incorporating professional care into their lives. The patterns help differentiate whether the interviewees (a) use developed care skills to contribute actively to the co-production with their layman knowledge, or (b) seek relief of their care responsibilities and withdraw temporarily from the direct sphere of care applying freed capacities to organise family daily life, or (c) use the services of the care centres to meet with other older people and to develop spaces for mutual help and co-production. The interpretive and practice patterns thus differ in the extent to which care users and family caregivers continue to play an 'active role' in the care process and contribute their own knowledge, ideas, expectations and particular care activities. In order to achieve a functioning co-production, professionals face the challenge of understanding these patterns that have been established over many years and of taking them into account appropriately.

KEYWORDS

care dependency, co-production, family caregivers, interpretive and practice patterns, older people, qualitative study, user experience

1 | INTRODUCTION

In Germany, 3.4 million people have been recognised as care dependent and receive Long-term Care Insurance (LTCI) benefits (Statistisches Bundesamt, 2018). LTCI was introduced in 1995 as a compulsory insurance. It provides within a single program universal coverage; benefits are irrespective of income levels and vary based on the disability level. The care insurance scheme facilitated a German-wide expansion of outpatient and inpatient care (Nadash et al., 2018). However, it covers only part of the expenses for LTC services; care in nursing homes, in particular, constitutes a risk of impoverishment for care dependent people.

In Germany, a total of 76% of the people in need of care are cared for at home, mainly by family members and most frequently by women (Statistisches Bundesamt, 2018). The care (of family members) at home often is a creeping process (Rohr & Lang, 2011), in the course of which an increasing number of additional and new care tasks has to be taken over. As a rule, the German LTCI favors family-centred models of care (Theobald, 2012), for example, by granting insurance cash benefits, relief care and pension insurance contributions for caring relatives. In recent years, there has been a growing awareness in German care policy that family care requires professional support (cf. Le Bihan et al., 2019). A well-coordinated ‘care mix’ of informal and professional help counteracts caregivers’ feelings of being overburdened and, at the least, may delay a move to a nursing home, thus stabilising home care (Spillman & Long, 2009). For a sustainable ‘care mix’, the co-production of informal and professional care is needed (Janse et al., 2018). The concept of co-production is considered essential to initiate processes that enable shared responsibilities and ‘real collaboration’ between ‘service recipients’ and professionals (Bovaird, 2007; Ewert & Evers, 2014; Fotaki, 2011). Co-production means that professionals are there to support and moderate health-related and care-related decisions made by users (their families and communities; Realpe & Wallace, 2010). Users of professional services are to be acknowledged and strengthened in their competencies (Ewert & Evers, 2014).

However, there is little evidence of how “users” and their families integrate professional support into their care arrangements, or why, in some cases, they prefer not to do so.

This article analyses the processes of (gradual) integration of professional care services into informal care arrangements by drawing on data from a qualitative study conducted to evaluate a pilot project in Germany (2016–2019). In this project, called “Rethinking long-term care institutions”, four nursing homes were expanded into local integrated care centres. This is a pilot project provided above and beyond the regular care offered by the nursing homes in Germany. In addition to long-term and short-term inpatient care, the pilot facilities established a flexible range of services for community-dwelling older people in the nursing homes’ neighbourhoods: Older people visit the centres to use a variety of open-door services (e.g., lunchtime meals; card games, health-promoting measures such as rehab training or strength and balance exercises); moreover some spend their day as daycare guests in these nursing homes. This daycare is not provided separately but integrated; that means, daycare guests spend their day together with nursing home residents and use the same services (Hämel & Röhnsch, 2019).

The care centres are located in urban neighbourhoods. They offer users and their relatives continuity of care from low threshold support up to living in a nursing home, if needed. One of the challenges the centres face is to cater for the needs of user groups in their diversity – guests from daycare or respite care; day visitors or course attendants with their different health impairments and different user intentions and requirements (Röhnsch & Hämel, 2019a).

What is known about this topic

- Care of older people is mainly shouldered by relatives in Germany.
- Professional support helps to stabilise home care arrangements.
- The concept of co-production is considered essential to initiate processes of shared responsibilities and ‘real collaboration’ between ‘service recipients’ and professionals.

What this paper adds

- The spectrum of behaviour that converts care dependents and their family caregivers into co-producers is broad. It differs in terms of how actively they wish to be involved in care procedures and how they integrate professional support into their daily lives.
- Integrated local care centres, which offer various services “under one roof”, facilitate the co-production of care based on long-established family patterns of dealing with care dependency.

1.1 | Aims/Objectives of the study

This study's objective is to explore how meaningful co-production of informal and professional care can be implemented. It analyses (a) how "users" and their families integrate professional help into their informal dealings with the need for care and support; (b) which patterns of co-production are evolving.

Our analysis focuses strictly on the users' perspective. It has been frequently pointed out that their subjective views on health and social care have been rather neglected in research (São José et al., 2016).

The present empirical analysis is a more advanced version of the research report published on PUB – Publications at Bielefeld University (Röhnsch & Hämel, 2019b).

2 | RESEARCH DESIGN

Insights discussed here are based on subjective views of care dependent older people living at home and their family caregivers. In order to reflect the diversity of care arrangements and utilisation of professional support offered at the centres, both users of open-door services (e.g. rehab training, lunchtime meals) and of professional nursing services (daycare or respite care) were recruited to be interviewed (Table 1).

Different approaches were chosen for recruiting participants: Employees of the care centres displayed the study details in the facilities' central meeting places and also sent this information by mail to all daycare and short-term care guests and their relatives. It thus primarily reached relatives who, when generally interested in participating in the study, approached the researchers, whose contact details were provided in the information letter. In two cases, already interviewed relatives facilitated contact with a care dependent family member, so that both relatives and users were interviewed (Table 2). In addition, research team members took part in various open-door services to specifically invite users to participate in the study.

Excluded from the study were those users, who in the opinion of relatives, staff of care centres or researchers taking part in open-door services, had too many severe cognitive deficits or were disoriented in terms of space and time. In these cases, their family caregivers were interviewed. A total of 26 persons were interviewed (Table 2). The interviews were conducted between November 2017 and August 2018.

All respondents were informed in writing and verbally about the study objectives and background. They gave their written consent to participate in the study. Interviewees decided whether they wanted to give the interviews alone or together with their relatives, in order to make them feel more comfortable and secure (Pesonen et al., 2011). The Ethics Committee of Bielefeld University gave approval to the implementation of the study (file reference EUB 2017-064). The assessment was carried out according to the ethics guidelines of the Deutsche Gesellschaft für Psychologie. All interviews were recorded, transcribed entirely and anonymised, also anonymising the names of the respondents.

The study participants were interviewed by means of an episodic interview guide (Flick, 2018). This form of interview combines the principles of narration and questioning by requesting interviewees to relate situations and episodes (e.g. "Would you say that [offer xy] makes your life better? Could you relate a situation to illustrate this?"). At the same time, they are asked to explain their experiences in a general and comparative way (e.g. "With regard to your health, are you suffering from a long-term chronic disease?"). In contrast with narrative interviews, episodic interviews do not require the interviewees to supply comprehensive narratives, but only to recall concrete events, situations or episodes around an event – which are recounted in "small-scale narratives" (Flick, 2018). Thus, this interview method is suitable for people with limited communication skills, e.g. due to emerging cognitive deficits, and for older people as found in our sample.

TABLE 1 Realised sample by location and type of services used

Type of usage	Locations of facilities 1	2	3	4	Total
Nursing care services	4	1	5	3	13
Open-door services	–	5[a]	1[a]	4	10
Nursing care and open-door services	–	1	–	2	3
N =	4	7	6	9	26

[a]Including one person each with experience as a caregiver and as a user.

TABLE 2 Overview of interviewees by age and gender

Age	Users *m*	Users *f*	Relatives *m*	Relatives *f*	Relatives and users *m*	Relatives and users *f*
50–59 years old	–	–	1	1	–	–
60–69 years old	–	–	–	4	–	–
70–79 years old	1	2	–	3	–	1
80–89 years old	6	4	–	–	1	–
≥90 years old	–	1	1	–	–	–
Total	7	7	2	8	1	1

The interview guide included bundles of questions regarding (a) the users' everyday life and social environment, (b) their health-related limitations and general care arrangements, and (c) the subjective perception and significance of the services/professional care used in the pilot facility.

These topics were the focus of both the guide for interviewing users as well as for interviewing relatives. Hence, both relatives and users were asked about their everyday dealing with care dependency the meaning of offers that the local care centres provide and if they meet their expectations; how the users' health situations are perceived by them personally or by their relatives. Relatives were also asked as to when and how they care for their care dependent relatives.

Data analysis was focused on working out interpretive and practice patterns related to co-production of care. These patterns are everyday theories, giving orientation, allowing situation-adequate actions and guidance for understanding and activities (Höffling et al., 2002). Initially, an identification of "themes" (superordinate or overarching categories) for further data analysis was performed deductively based on the interview guide contents. All statements of such a topic – e. g. challenges of everyday care arrangements – were thematically and case-specifically openly coded (Flick, 2018) using MAXQDA 12. For this purpose, the respective text was broken down by sensitising questions (Strauss, 1987; cf. Flick, 2018). Additionally, cross-case comparative dimensions were determined on the basis of similarities and differences between the individual interviews (Kelle & Kluge, 2010). Finally, the cases – thematically relevant interview sections – were grouped together and analysed comparatively along these dimensions and their characteristic values with regard to the occurrence of certain feature combinations. For this purpose, they were first compared within a group on similarities by means of case contrasting. It was expected that subsequent case comparisons between the groups would clarify any existing differences (Kelle & Kluge, 2010).

This way, three types of interpretive and practice patterns were determined, which were then analysed and interpreted in their context of meaning.

Data analysis was conducted by the first author of this paper in very close and frequent consultation with the second author. Ambiguities and inconsistencies in analysing interview material were discussed to reach a consensus; where necessary the coding was revised.

3 | FINDINGS

The three types of interpretive and practice patterns identified are: (a) focus on developing care expertise, (b) focus on relief of responsibility, and (c) focus on social support and mutual self-help.

3.1 | Focus on developing care expertise

This pattern is mainly found among the relatives of local care centre users. It characterises a process, in which the interviewees gradually become (lay) experts in this field due to their experience in caring for a family member. This pattern type applies to five interviewees. During their long carer ‘career’, they have learned to think along the structures and rationales of the formal care system. They can assess what needs to be done when their relatives' health situation becomes more acute and which professional they then need to contact. Based on their experience, the interviewees try to negotiate care processes with specialists in the care facilities and to assert their own views and expectations.

> So, I said [to a station employee in the care facility - the authors], what does that mean, ‘I will call a doctor now’? You know that my husband is enrolled in palliative care '(…) [She] did not even look at the computer, that was routine (…) the result would have been, the [doctor] would have come and sent my husband to hospital. Yes, and that's exactly what I wanted to prevent. (Mrs. Friese, 268)

The interviewees organise and coordinate the care and treatment of their relatives. They assume nursing tasks, but also access relatively early the support of home care services, if they are able to care for their dependent family member only to a limited extent, due to own illnesses or professional obligations.

Even if their relatives' care is taken over increasingly by nurses, the interviewees remain involved in the care and know how to assert themselves in their role as experts on the care of their relatives. In order to cope with the associated challenges, they also attend informational meetings and classes in the local care centres, which enable them to expand and enhance their existing knowledge. Respondents experience these opportunities as very helpful. The meetings, classes and activities offered help them to understand their situation and in part to put things into perspective. Finally, they provide the interviewees with opportunities to interact with people in similar situations.

> (…) the hospice care (…) after the classes (…) I did not become more stupid (…) that is quite trivial now, but I also met other people who possibly deal with such things differently or maybe were not so emotional. (Mrs. Friese, 210)

However, interviewees often find it difficult to share their responsibilities with the nursing staff. They also criticise nurses' behaviour at the pilot facilities, whereby the spectrum of grievances is quite broad. Thus, they complain that they are not always informed about their relatives' health crises or incidents at the facilities, such as the patient falling. They also fear that their relatives are being neglected when nurses are unresponsive in the event of questions. The interviewees perceive such occurrences as breaches of trust; they feel deceived and are disappointed in the face of what is perceived as half-hearted excuses offered by the professional caregivers in their defense. However, they feel strong enough to complain to the management about inadequacies they experience and to defend their own positions vehemently against any objections.

> (…) then it always sounded as if the [welfare worker] was trying to blame us (…) but they [in the care centre] were wrong not to inform us, (…) in any case, [it went] back and forth, and then we got nowhere with it (…) it was a tough fight, I must say. (Mrs. Bruns, 101)

3.2 | Focus on relief of responsibility

Respondents who quickly adjust to routinely utilising daycare or (recurring) respite care services at the integrated local care centres are classified in this interpretive and practice pattern. The interviewees emphasise that they no longer feel capable of dealing with the complex daily challenges of care and are relieved to be able to hand over responsibility to professional care providers (also) at the care centres. Nine interviewees (seven relatives and two users) fall into this pattern. They make it clear that over time, the difficulties of family care have become acute, and that they have gradually lost ‘control’ over the situation.

Caring relatives, who also are (very) old and must deal progressively with their own personal health problems, are overwhelmed by the acute health situation of the dependent family member. Users who are dependent on support or care themselves, perceive that the efforts of relatives to care for them have reached their limits.

> My grandson looks after me after all, but he has his own business to do (…) my daughter-in-law is also ailing, my son is ill, they already have to look after him. (Ms. Faber, 23)

In the opinion of relatives and users surveyed, the utilisation of professional assistance appears to be unavoidable. It becomes a strategy in dealing with care needs and enables, in particular, the family caregivers to regain the capacity to act in everyday life. This also includes an attempt to create at best a little free space for themselves for pursuing their long-time hobbies.

The interviewees implicitly are predisposed to a prospect, in which the "professionals" are mainly responsible for all care questions. Caring relatives report that they only 'know' little about chronic diseases, care dependency and related care needs. They consider their efforts to exclude themselves from care issues being in the interest of the dependent family member.

A tendency to delegate responsibility is also found amongst help and care dependent users of this group. They are unaware of their own illnesses and the background of their former care. It is a relief to be able to rely on professionals and their know-how.

> I wouldn't know, if they could have helped me (…) if the hospital says there's nothing you can do, I have to believe them. (Ms. Frings, 68–70)

If the caring relatives are convinced they have provided their family members with good professional care, this frees them emotionally and physically.

> (…) it is simply the fact of not to be worried about what the other now needs. It is simply to know that the other is well looked after now. (Ms. Becker, 148)

The interviewees then have more time and energy to attend to the organisation of everyday life at home. They arrange the preparation of meals, take over routine household tasks or garden work. Thus, they ensure that long-time family routines are maintained as far as possible, thereby conveying a sense of normality despite the care dependency, for example when interviewees are trying to organise the leisure time with their relatives in the usual way, such as going for walks or watching TV in the evenings.

The respondents in this group are very satisfied with the local care centres and their integrated services. They appreciate the fact that the centres – in contrast with exclusively ambulatory facilities – are always 'open' and accessible; this allows them to take advantage of professional support individually, promptly and according to their needs. In addition, the interviewees found the caregivers in the centres to be professionally and socially very competent. They (implicitly) state not to have those skills themselves. Therefore, they do not appear to be entitled to negotiate with the caregivers they regard as experts in this care arrangement.

> (…) this is also one [professional caregiver in the care centre] that has great people skills; that's what I admire so much (…) in old age they all have their quirks (…) but how they deal with that, that is unique(…)(Mr. Lehmann, 13)

3.3 | Focus on social support and mutual self-help

This pattern is characterised by the fact that when interviewees – exclusively users, no relatives – make use of the centres' offers, they mainly relate this to the option of meeting other older people there with whom they can exchange assistance.

Some of the interviewees suffer from multiple chronic diseases, which require or in the past required phases of long-run, partly stationary treatments and a considerable amount of care.

Nevertheless, the interviewees convey a picture of themselves implying that their own need for care is a problem that at most affects them only marginally. In their view, they have managed to live a largely "normal life" despite chronic illnesses. However, they seem to suffer from a lack of close social relationships. Frequently, once retired their spouses become the closest, and frequently their sole social contact in life. The loss of spouses and close friends through death often leaves them isolated.

If these interviewees use daycare, attend midday meals, card games or exercise classes, they meet other older people who have experienced the same hardships, e.g. a spouse's death. This gives them a sense of understanding and security. The interviewees feel part of a fellowship, of mutual emotional support. Comparable to an informal self-help group, they act largely independently from the professionals of the facilities, "(…) *we like to come here to talk and amuse ourselves, and that's a fine thing*" (Mr. Fein, 137).

The respondents are particularly pleased when they meet up with old acquaintances at the local care centres, whom they had lost sight of and can now re-establish contact. This opportunity signifies – long missed – personal attention, when the interviewees experience that other older people, whom they encounter at the care centre, are pleased to see them.

The interviewees also try to look after other users, who appear to have more serious health problems than they have. This is conducive to their sense of purpose, significance and self-worth. At the same time, they take the pressure off professional caregivers and become co-producers of care.

> (…) he has got this Parkinson's disease (…) when he talks he sometimes loses the thread, starts to shake (…) I always tell him "Walk slowly, make large steps". That's what the nurses always tell him as well. (Ms. Löwe, 78)

When the interviewees from this group congregate with other older people to exchange views, take the emotional load off or arrange further meetings, they do not all the same act independently from the centres, which offer them the conditions for those meetings by providing the locations in the first place. When the interviewees make use of care centre offers, such as rehab training or lunchtime meals, this also contributes to stabilising their health and releasing them from everyday duties, which may easily overstrain them. As a consequence, they are provided with new resources for building up and maintaining social relationships.

> I have never cooked (…) if I were to cook may be a bean soup today (…) I wouldn't know how many beans to buy (…) should I take a small tin or a large one. The large one, I certainly won't want to make bean soup again tomorrow – it will probably go off then (…) it is a blessing not having to waste much thought on this. (Mr. Flieder, 167)

4 | DISCUSSION AND IMPLICATIONS

This study enabled us to identify several coproduction-related interpretive and practice patterns among users of local integrated care centres and their family caregivers. These patterns reveal how informal care and professional support intertwine and how co-production of care is realised on a daily basis. The interviewees differ significantly in their desires, expectations and also the perceived need to arrange the care using co-production (similar Puurveen et al., 2018).

4.1 | Focus on developing care expertise

A few study participants have over time acquired considerable (nonprofessional) knowledge in the nursing field, and are, therefore, to be regarded as “expert users” (Lindsay & Vrijhoef, 2009). As such, they have clear expectations concerning their relatives’ professional care, and want to be perceived and addressed by the professionals as active co-producers. The interviewees point out that their relationships with the staff are based on mutual respect; the question 'who is the boss here' rarely arises (Austin et al., 2009). Studies have shown that relationships between relatives and health professionals, which are based on a partnership, can help care dependents view their respective care settings as ‘their community’ and as a kind of ‘new home’ (Bauer et al., 2014).

Our results reveal that it is very important for “lay experts” that health professionals make their care process strategies sufficiently transparent to them. This can be seen as a prerequisite for “successful” co-production (Austin et al., 2009). Therefore, professionals should, where possible, include them in the care coordination, as well as in practical day-to-day care responsibilities. At the same time, it is important that they inform ‘users’ of the principles which guide their care.

4.2 | Focus on relief of responsibility

One-third of the study participants chiefly seek relief from their burden of care when using the local care centre's services. When these interviewees are convinced that their relatives are well-cared for, they withdraw at least temporarily from the direct sphere of care. Relinquishing care responsibility could be an expression of being overwhelmed by the role of active co-producers (Pickard & Rogers, 2012). If the interviewees in this study regard the professional caregivers in the care centres as experts, whose care-related recommendations they, as nonprofessionals, appreciate, this act of upholding a traditional “user role” as a service recipient renders a feeling of security in a situation, which often enough is overstraining due to chronic diseases and care dependency (see also Ewert & Evers, 2014).

However, according to our analysis, the pattern of relieving responsibility does not represent a withdrawal of responsibility in co-production in general. On the contrary, it can be understood more as a functional separation of responsibility between professionals and relatives/users, which the latter actively demand. While professionals focus on the role intended for them and undertake care temporarily or periodically, the family members here use their freed capacities for their own relaxation or for providing other kinds of support, in particular, by participating in joint social activities. According to an international review (Crespo et al., 2013), adhering to daily routines in this way can lead to a sense of continuity and contribute to a feeling of normality despite chronic illnesses and care dependency within families (see also São José et al., 2016). The fact that the interviewed relatives are also able to maintain hobbies whilst their relatives are looked after in local care centres can strengthen their own health and thus also the home care arrangements (Frewer-Graumann, 2020).

In summary, family caregivers and care users with this interpretive and practice pattern need additional guidance from professional care workers to generate meaningful co-production. This is particularly true when care-relevant decisions or choices between different services and therapies must be made. Professional caregivers should grant care dependents and their relatives the “right not to know” when arranging co-opted care, as is discussed, for example, when dealing with serious, incurable diseases (Blackhall, 2013), and thus satisfy their needs for autonomy.

4.3 | Focus on social support and mutual self-help

Half of the study participants have come to terms with their own health limitations. The respondents are more concerned about having largely to fend for themselves in everyday life and having few or no social contacts. If interviewees, whilst visiting the care centres, congregate with other older people, communicate and feel understood, this implies a considerable social support, which means more to them than receiving instrumental help, e.g. offered meals. Respective studies revealed that the possibility to establish meaningful peer relationships is an important factor enabling a sense of belonging also to institutionalised support settings, which are forming a “framework” for those relationships (Kang et al., 2020). The sense of belonging, in turn, is a prerequisite for interviewees being an active partner in the care and thus becoming co-producers – by looking after other users, for instance. In this respect, co-production also means that users support each other; it goes beyond their own care arrangements. Responsive and trusted friends who help dealing with everyday practical matters are also an important resource for integrating illness and also care dependency into daily life (Whittemore & Dixon, 2008) and coping with symptoms and secondary disorders (Audulv et al., 2012). For those who show this interpretive and practice pattern, co-production represents above all the strengthening of social participation. This is where the further development of services offered could begin promoting more focused group-based interaction and co-production of users and professionals addressing health and care issues.

4.4 | Strengths and limitations of the study

One of the strengths of our study is that it emphasises the contribution of integrated local care centres to co-production in long-term care from the point of view of users and caring relatives. This study takes into account that their perception of care has so far been neglected in research (São José et al., 2016). While one strength of the study is to give a voice to local care centre users, its weakness is that it fails to heed to the care provider perspective. Therefore, in order to gain deeper insights into the possibilities of co-production in long-term care, future studies should take the professionals' perspective into account, because co-production is demanding for them as well (Bovaird, 2007). Furthermore, the subject of co-production needs to be examined in a longitudinal study, since the provision of care itself or the needs and capacities of care dependents and their relatives to get involved in the healthcare can change for various reasons over time (Harvath et al., 2020; Puurveen et al., 2018).

In addition, it is possible that mainly users and relatives who tend to have a more open and positive attitude towards the care centre's services were selected for participation in the study. In their case, the co-production of healthcare may well be considered less "problematic." Another sample might have identified more conflicts between relatives/users and professionals, a fact that would also have been important for the issue of a suitable co-production of health care.

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CONFLICT OF INTEREST

The authors declare no conflicting interests.

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DATA AVAILABILITY STATEMENT

Author elects to not share data.

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