Providing support for family carers: social workers describing their professional role

Åsa Alftberg

To cite this article: Åsa Alftberg (23 Dec 2023): Providing support for family carers: social workers describing their professional role, Nordic Social Work Research, DOI: 10.1080/2156857X.2023.2297978

To link to this article: https://doi.org/10.1080/2156857X.2023.2297978

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

Published online: 23 Dec 2023.

Submit your article to this journal

Article views: 5

View related articles

View Crossmark data
Providing support for family carers: social workers describing their professional role

Åsa Alftberg

Department of Social Work, Faculty of Health and Society, Malmö University, Malmö, Sweden

ABSTRACT
Family carers have a growing significance, and they are increasingly regarded as clients in need of support. In Sweden, the municipal support for family carers is often provided by family care advisors. However, there is a lack of knowledge regarding this relatively new area of social work practice. This article aims to explore how family care advisors describe their work and construct their professional role in relation to family carers. The empiric material derives from a research circle, a form of focus group interview, with family care advisors. The theoretical framework is based on the concept *categorical pair*, where the description of the family care advisors’ work includes constructing themselves as professionals and the family carers as clients. Four themes have emerged in their stories: being neutral, being allies, being a container, and being an educator. The findings show how the family care advisors’ relationship with the family carers is described as being simultaneously personal and professional: a form of *professional friendship* with a delicate balancing act. The family care advisors also view their neutral role, with no power to exercise authority, as important and required. Family carers that are perceived as difficult are described from a paternalistic perspective, thus needing to be educated by the family care advisors. Accordingly, when the family care advisors construct their professional role, they also construct family carers, which includes implicit moral notions of a ‘good carer’.

ARTICLE HISTORY
Received 10 February 2022
Accepted 10 December 2023

KEYWORDS
Informal caregiving; family care advisors; categorical pair; professional friendship

Introduction

In 2009, a clarified provision was introduced in the Swedish Social Services Act. This provision stipulated that the social services are obliged to (instead of the previous should) offer support to family carers who provide regular, informal care for a relative who is old, long-term ill and/or has a disability. The purpose of this support is primarily to reduce the carers’ physical, mental and social burden, and to reduce the risk of ill health (National Board of Health and Welfare 2016). How the provision has been implemented in the social services differs, but most municipalities have one or several social workers specifically assigned as family care advisors or the equivalent in their functions (National Board of Health and Welfare 2014). The family care advisors work with specialized support aimed directly at family carers, and they are often responsible for spreading and developing the support for family carers within the social services (Winqvist 2016). Thus, family care advisors are central for the content and development of the municipalities’ support for family carers. However, there is a lack of knowledge in this relatively new area of the social work profession, including family care advisors’ perceptions and experiences of working with family carers.

CONTACT Åsa Alftberg asa.alftberg@mau.se

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.
**Aim**

This article aims to explore how family care advisors view their work and construct their professional role. The study seeks to answer the following questions: How do family care advisors describe their work with family caregivers, and how do they explain their professional assignment in supporting family caregivers? The purpose of the study is to highlight a new area for social work practice, which is the support provided to family caregivers and the relational foundation of that support.

**Family caregiving – a Swedish context**

Many family carers in Sweden are seniors providing care for spouses in a joint household. Among family carers aged 65–80, 37% care for a spouse, while the figure for those over 80 is 77% (Jegeralm and Sundström 2015; National Board of Health and Welfare 2012). Adult children caring for a parent constitutes another large group of family carers (SFCCC 2021). Family care in general is primarily aimed at relatives with dementia, but also those with mental illness, addiction or substance abuse problems, as well as children with disabilities. Children are also beginning to receive attention as family carers, for example caring for parents with mental illness or ageing grandparents in generational housing (Takter 2020). Nearly one-fifth of the adult population in Sweden provides care to a close relative at least once a month due to illness, disability or old age (National Board of Health and Welfare 2014). It is estimated that women perform two-thirds of the care of relatives (SFCCC 2021).

Family care (or informal care) is sometimes combined with formal care for the care-dependent person. In such cases, home care is often combined with home health care, which is means-tested by a care manager at the municipality. Only the care-dependent can apply for support, not the family carer. Care managers ‘investigate and assess, based on the law and prevailing rules, cases involving various forms of assistance requirement for which the municipality has some responsibility’ (Wallroth 2016, 131). In this process of decision making, family caregiving should not be taken into account. However, in practice, it has been shown that the access to family care does matter and affects how formal care is planned and executed (Takter 2017).

Family carers are often perceived as aides to formal caregivers, rather than clients in their own right (Gerrish 2008; Guberman et al. 2006; Takter 2017). This is in line with the typology of informal carers by Twigg and Atkin (1994), where the main model identifies family carers as resources. This entails that family carers are expected to be available to the formal system of care and support for the care-dependents. Even though the other models of Twigg and Atkin can be identified, for instance informal caregivers as co-workers or co-clients in the eyes of the care professionals, a predominantly instrumental perspective on family carers has remained (Manthorpe, Iliffe, and Eden 2003; Söderberg, Stähl, and Melin Emilsson 2015). Nevertheless, the formation of family care advisors as a new area of social work practice considers family carers as clients in their own right and in need of support.

The emphasis on family carers as clients coincides with increased expectations of family carers: supporting informal caregivers could ease a potential lack of resources in formal care, for example elderly care (Szebehely 2005; Szebehely and Meagher 2018; Ulmanen and Szebehely 2015). That family carers volunteer to help and support an ill relative is no longer emphasized. Rather, the starting point is that family carers need support in their caregiving role. Therefore, the choices available for family carers seem to have weakened when it comes to choosing what responsibility they want and are able to take on (Johansson, Sundström, and Hassing 2003, Johansson et al. 2011; Takter 2017; Winqvist 2016). Leinonen (2011) links this development to the ageing of populations and to difficulties in national economies, thereby leading to a reduced amount of formal care, such as home care services and residential care homes. Thus, many older people with less intensive care needs have to rely on their family members (Leinonen 2011). This development concerns not only
elderly care but also, for example, parents’ care of children with disabilities, where formal obligations are transformed into family responsibilities (Olin and Dunér 2016).

**Support for family carers**

Support for family carers is based on a psychosocial model aimed at providing support and teaching coping skills (Shanley 2008). Shanley (2008) describes this as a continuum, where one end is educational with the purpose to provide information. The midpoint of the continuum is support in the form of discussing personal issues, sharing feelings and providing emotional support. The far end of the continuum is therapeutic and explores personal issues at a deeper level. However, no point is more valuable than any other point: they are all relevant and necessary.

In practice, support for family carers may be both direct and indirect. Direct support is specific carer support, while indirect support is more help as a by-product, meaning that some forms of support for the ill relative may benefit the family carer as well (Jegermalm 2003). In Sweden, family care advisors work only with direct support. The different forms of direct support that are possible within the social services are meeting points for family carers, health-promoting activities, support groups and individual counselling with family care advisors (Winqvist 2014). The individual counselling is not therapeutic; rather, it comprises informative and supportive conversations that the family care advisors offer to interested family carers. The support is voluntary and is not officially documented or registered (Alftberg 2020).

**Theoretical framework**

When studying a relatively new area of practice for the social work profession such as family care advisors, it is important to address ideas about professionalism and professionalization. Theorizing professionalism in social work concerns the development of the perspective of social work as a human rights profession. Social vulnerability and social justice are central concerns, and human dignity, participation and non-discrimination are core principles (Reynaert et al. 2022). This approach to social work includes distancing from the perspective of social work as a caring profession, which is associated with paternalism, surveillance and oppression. However, seeing care as a central principle of social work may offer useful insights to the practice of social work (Lloyd 2006). A feminist ethics of care challenges ‘the abstract ideal of the independent, autonomous individual’ (Lloyd 2006, 1183). Instead, care is seen as a fundamental aspect of all human experience (Tronto 1993). Family care advisors can be considered as a caring profession from this perspective, if care is considered to be all forms of activities people do to maintain and mend their world so they can live in it as well as possible (Fisher and Tronto 1990). The family care advisors perform a formalized care that aims to mend as much as possible the world of the family carers (Alftberg 2021).

While professionalism can be regarded as a mode of practice, professionalization is a process of defining the boundary between profession and non-profession, as well as between professions (Heite 2012). The process involves agreeing upon definitions of reality and ‘claiming, and recognizing, that a certain field of occupational action is a professional field or is in need of professionalization’ (Heite 2012, 2). Family care advisors can be viewed in two ways: as a recognition of a social problem, which is the exposed situation of family caregivers, or as a means to point out and claim new areas for professional social work. This article is interested in how this process occurs, specifically how family care advisors describe their work and construct their role.

The theoretical point of departure in this article is Tilly’s concept of categorical pair (Tilly 1999). A categorical pair consists of a socially significant boundary between two parties that are unequal. It is a relationship between two actors, each representing the characteristics of the category it belongs to. Professional/client is one example of a categorical pair, according to Tilly. The category ‘professional’ represents the power and
preferential right of interpretation, based on education and organizational affiliation. The category 'client' represents an inferior position, with personal circumstances that needs to be met (Svensson 2005).

Tilly defines categories not as specific sets of people but as standardized, movable social relations. Categories also generate stories: “stories that participants subsequently use to explain and justify their interactions. The stories embody shared understandings of who we are, who they are, what divides us, and what connects us” (Tilly 1999, 63). The categorical pair in this article, family care advisors and family carers, include stories, i.e. distinctive qualities attributed to actors on either side of the boundary (p. 67). When the family care advisors describe their work and their professional role, they do categorical work. They construct a categorical pair consisting of family care advisors and family carers. Moreover, they ascribe characteristics not only to their own group of professionals but also to family carers. How categories are negotiated and shaped is important to study because categories have significance for how we perceive those who are categorized (Hacking 2000). To use Jenkins’ (2000) concepts, the family care advisors construct both a group identification (family care advisors) and a social categorization (family carers).

Material and methods

The empirical material derives from a research circle with family care advisors, which focused on their assignment and everyday work. A research circle is a participatory-oriented method, where the researcher and participants (often professionals) co-create knowledge of a subject (Andersson 2007). The form has similarities with focus group interviews and can be regarded as a modified focus group method (Stewart, Shamdasani, and Rook 2007), but the participants decide more freely what they want to talk about. The researcher takes part in the discussion and ensures that topics are not taken for granted, but problematized and illuminated from different perspectives (Andersson 2007).

A professional network of family care advisors were asked to participate in a research circle led by the author, focusing on their tasks and experiences of being a family care advisor. Nine family care advisors chose to participate. Over an eight-month period, they met on six occasions, each lasted about two hours. Prior to four of the meetings, selected scientific texts were read to provide a thematic inspiration for the discussions. The themes were suggested by the author and based on the participants’ views and wishes discussed during the first meeting. These included professionalism, ethical stress and communication barriers between professionals and clients. During the last meeting, the previous discussions were summarized.

The participants, all females, had worked as family care advisors in the social services in different municipalities between one and eleven years. Several had also previously worked in situations where they had met family carers in different spheres, for example in health care, but at that time their work was not particularly aimed at family carers. Thus, the participants shared common ground – a concept that captures how the participants could use their existing roles and professional identities as a basis for interaction. This meant they had a mutual vocabulary and could interact more confidently knowing there was mutual understanding within the group (Morgan 2019). A common ground not only benefits the discussion but may also lead to statements that contain a lot of tacit knowledge. Accordingly, the role of the author was to ask questions to clarify and to problematize the discussions. However, with the combined knowledge and experiences of the participants, the author’s role became more withdrawn, with a greater focus on listening than partaking in the discussion.

The empirical material consisted of digital recordings of each meeting, which was later transcribed verbatim by the author. Then, a thematic analysis of the material was made. A thematic analysis is a process for identifying patterns of meaning in qualitative research (Braun and Clarke 2006, 2013). The process should be viewed as ongoing and organic, and the researcher needs to be reflective and reflexive (Swain 2018).
The analysis started with several readings of the transcriptions with an inductive approach to interpret the meaning in the data. Words and sentences that seemed important to the description of the family care advisors’ work were highlighted and sorted into preliminary themes. Finally, four themes emerged from the empiric material. The themes were then placed and tested within a theoretical framework in order to critically understand the findings (Carey 2012). The theory also functions as a facilitator in questioning taken-for-granted assumptions by providing a description of characteristics of the social world (Gibson and Brown 2009; Saldana 2011).

**Ethical considerations**

The family care advisors gave informed consent to participate freely in the study. Presumptive participants received information about the study and those interested contacted the researcher, not vice versa. Informed consent was given in two steps: firstly, informed consent to participate in the research circle; secondly, informed consent that the empirical material from the research circle be analysed and published. The material contained experiences of the participants’ professional assignment and everyday work. Moreover, the conversations during the research circle were led by the author with great sensitivity to any anxiety or discomfort that might arise due to the current topics. In the article, the participants have been pseudonymised, and any information that could lead to recognition has been altered. The study does not fall under the Swedish Ethical Review Act since no sensitive personal data were obtained.

**Findings**

Four themes emerged in the analysis that described the professional role towards the family carers: being neutral, being allies, being a container, and being an educator.

**Being neutral**

The family care advisors considered their role as rather informal compared to other social workers within the social services. They have no power to exercise authority, and the support they offer to family carers is voluntary and in no way officially documented or registered. Receiving support does not come with any requirements, and the family care advisors have no connection to the care-dependent nor to the formal care for that person. The family care advisors described themselves as a neutral part – focusing exclusively on the family carer – and as neutral interlocutors, someone the carers could talk to about their situation and their feelings. A family care advisor is someone on the outside, ‘almost like a private person but still a professional’, as expressed by one participant; a professional with insight to the care system that the family carers and their relatives are part of.

Being neutral and exercising no authority within their assignment seemed to indicate a perception of an equal relationship with the family carers:

I believe it’s about being more equal in the relation when you have a relation with family carers than, for example, doctors and patients, or case managers and clients. They have such an imbalanced position of power, which we can avoid.

The feeling of equality was enhanced by the fact that the family carers can often choose where they want to meet the family care advisor. The meeting may take place in the carers’ homes, in a café, or in the office of the family care advisor. Particularly, the office was described as a neutral place, with no connotations to the carers or their relatives. Being neutral appeared important and seemed to mean different things: non-official (including no exercise of authority), no connections to the relatives of the carers, and having an equal relationship with the carers. From the perspective of categorical pairs, an equal relationship cannot be established between professionals and clients. However, when the typical props for authority and power, such as documentation, are absent, the relationship can be perceived as equal by the family care advisors.
**Being allies**

The family care advisors also viewed their professional role as forming an alliance with the family carers. The alliance is built on the often long and close relationship that emerges between the two parties. According to the family care advisors, the family carers usually feel that they have to deal with their situation alone, with the family care advisor being their only ally in an otherwise uncomprehending world. Consequently, the relationship becomes close and emotionally bound, and the carers may share very private elements of their life:

> Many carers you meet are in a vulnerable and exposed situation, and they enter the room with lots of emotions. Sometimes, you meet spouses who talk about leaving someone who is ill, which stirs a lot of emotions and shame: 'Is it okay to feel what I feel?' And there is a lot of stigma: 'Do I dare to say what I’m saying now, since it’s not really okay to say and feel what I feel?' The family care advisor is perhaps the very first person they say this to. They have kept it hidden inside; it’s the first time they say this aloud. And then, we are the people who receive this.

The family care advisors highlighted that although individual counselling is special and important, it can also be difficult sometimes. For the carer to confide in them, they need to establish a sense of trust. Furthermore, they must guide the conversation in such a way that the carers are energized afterwards. At the same time, the counselling is not supposed to be therapeutic.

The alliance is encouraged by the relationship’s emotional content, but it may also become too close. The participants stated that the family carers sometimes connected and felt a sense of belonging in relation to them, but in a way that was not intended:

> You may end up in a position where the family carers attach themselves to you in a way that wasn’t intended. And you may not have encouraged that. But having someone who listens to you can be very, very powerful for the carers. Especially if it lasts for a long time.

Building professional or working alliances (Bordin 1979) is central to all social work interactions. Professionals use their interactional skills — including personal, relational, and empathic qualities — to produce mutual trust and understanding (Koprowska 2020; Nilsson and Olaison 2023). However, family care advisors experienced that it can be difficult to keep the alliance on a proper level: close, but not too close. Importantly, being an ally to family carers did not mean losing one’s professional role

**Being a container**

The emotional alliance described above also led to consequences for the family care advisors. They could sometimes feel like a container: ‘We fill this container function . . . people [the carers] unload on us’. The carers’ difficulties and challenges could weigh the family care advisors down, as reflected in the following discussion:

Family care advisor 1: It sticks with you if you don’t have any way to vent your own emotions.

Family care advisor 2: It’s not always the number of meetings or conversations. It’s also about what happens in the meetings and how I can cope with that. I may have several meetings and feel that they were good meetings; you feel light at heart when you finish. But I may have one that weighs me down for a long time.

In consequence, the container function risked leading to compassion fatigue, i.e. ‘a state of exhaustion which limits the ability to engage in caring relationships’ (Nolte et al. 2017, 4365). As one participant declared: ‘when everything feels hard and you don’t have the strength to be the professional you want to be’. The container function and the risk of compassion fatigue highlighted the importance of finding individual coping strategies. The family care advisors revealed different strategies, for example limiting the number of counselling sessions per week. Because the profession is emotionally demanding, care advisors have to distribute and limit both time and energy to avoid exhaustion. Another strategy was to set aside time to write down thoughts and reflections or talk to
a colleague: What was actually said at the meetings with the family carers? Could and should something have been said in a different way, or raised from a different perspective? Time for reflection provided the opportunity to analyse one’s efforts and valuable input for the subsequent meeting. A third strategy was professional supervision, where the opportunity to raise difficult issues and dilemmas, and put them into perspective, was perceived as a mode of recovery. Though only a few of the participants had access to professional supervision, they all saw this as something important.

**Being an educator**

Family care advisors perceived that family carers at times had unreasonable or mistaken expectations; consequently, they had to assume the role of an educator. Despite best efforts to be clear and distinct about the available support, they found that some carers’ expectations exceeded what was on offer. Such carers were described as difficult or demanding. For instance, the family care advisor could be expected to function as a therapist or psychologist, or, would have to ‘take over’ the carer’s situation and make difficult decisions such as deciding whether to apply for residential long-time care for the ill relative. Another common expectation was for them to persuade a reluctant relative to accept formal care and support, for example home care. In such situations, the family care advisors were seen as part of the family: as a daughter or a sister, that is, someone who is naturally there for the family when needed. Furthermore, they related how they sometimes were expected to side with the family carer in any conflicts that arose with the formal care system. In such difficult situations, their approach was to guide and to educate the family carers into having more reasonable and realistic expectations.

Another description of carers in need of guiding and education were those who disputed the professional knowledge of the family care advisors. Although the family carers saw themselves as knowledgeable, the family care advisors believed they had inaccurate or irrelevant knowledge regarding their specific situation:

- **Family care advisor 1**: Sometimes, family carers know much more than I about legislation and medicines and diseases and everything. It happens a lot, and they are quite right. But I also encounter family carers who know very much, but it is the wrong facts and the knowledge they have gathered is… It doesn’t fit. Their expectations are not at all in line with what is reasonable or possible.

- **Family care advisor 2**: I see in front of me – those persons who are knowledgeable, but from their perspective. And therefore, when you talk to them, they explain to you how to do it right. But this is not in line with the prevailing view on how we should interpret legislation and other things. Then you have to try to explain that.

Such carers may produce feelings of frustration for the family care advisors, which, of course, cannot be displayed. The participants explained that when faced with such challenges in their professional role, they reminded themselves of the family carers’ stressful situation and the difficult choices that carers may encounter, sometimes including making decisions on behalf of someone else. On the whole, carers that were perceived as difficult were described as exceptions, and that the majority of family carers had realistic expectations of the support they may receive. In particular, those carers that the family care advisors perceived as having a strong sense of coherence and who seemed to experience the overall situation as comprehensible and meaningful were the easiest to work with.

**Discussion**

The findings show how family care advisors viewed themselves both as neutral and as allies in relation to family carers. This is in line with previous research, which indicates that the professionals’ support for family carers seeks to reduce their burden and offer moral support and encouragement (Guberman et al. 2006). Being neutral and being allies seems to convey
a desirable professional role, while the description of being a container highlights the emotional strains of the profession and the risk of compassion fatigue. Compassion fatigue is frequently related to organizational structures and models, but it is commonly understood as individual responsibility (Kreitzer, Brinntell, and Austin 2020), which can be seen in the descriptions of the family care advisors who tried to find individual strategies to cope with emotional stress. In turn, being an educator underlines the fostering and educating approach to family carers who were considered difficult. This can be interpreted as a paternalistic attitude towards the family carers (Mossberg 2016). The carers need to be taught the right expectations and the right knowledge for their own good. This strategy may also be understood as a means to handle perceived challenges to the professional identity (Lilliehorn, Isaksson, and Salander 2021).

In practice, family care advisors may take several of these roles in one conversation with a family carer. For instance, being a neutral educator underlines the informative and knowledge-bearing aspects of the profession, while being an allied container emphasizes the emotional support that is needed. More complex roles may involve being a neutral ally or a container who educates.

The term professional friendship may be an accurate description of the balancing act between these various roles and the close relationship between family care advisors and family caregivers. The close personal contact has friendship-like qualities, but it is contained within professional boundaries (Reimer 2014). One friendship-like quality is the feeling of a mutual and equal relationship. This connects to the experience of the family care advisors being a neutral part, where neutral seems to mean the perception of having an equal relationship to the carers. Nevertheless, the family carers that are perceived as difficult are not part of an equal relationship but are described from a paternalistic perspective: they must be educated by the family care advisors.

The professional friendship takes place within professional boundaries, to which there appears to be a constant threat, especially when being allies. To be recognized as a personal, rather than a professional, friend or confidant threatened the professional boundaries – boundaries that already may be experienced as vague due to the lack of exercise of authority and formal documentation. Even so, the alliance between family care advisors and family carers appears to be defined on the family care advisors’ terms, not the family carers’.

The relationship between family care advisors and family carer could also be interpreted as a dual relationship, where the relationship is simultaneously both personal and professional. Normally, the concept is used to describe situations where social workers have other forms of contact with service users outside of the work, thus highlighting the overlapping roles and relationships in small communities (Pugh 2007). However, the trust and confidence that this term captures seems relevant here. In addition, the notion of a neutral professional role and professional objectivity has been criticized as inappropriate, creating unnecessary boundaries and unrealistic expectations (Green, Gegory, and Mason 2006). Still, the family care advisors perceived their neutral role as important and required.

The descriptions of the professional role are part of the construction of a category, or a categorical pair. They create stories of what family care advisors are and what they do (Tilly 1999). In the stories of the professional category, there are also stories about the client category: the family carers. For instance, through describing carers that the family care advisors perceived as difficult, an implicit description of a good carer appears. A good carer does not cross any professional boundaries but respects them and the professional knowledge. Moreover, a good carer has a close, but not too close, relationship with the family care advisor and does not have excessive or erroneous expectations of the offered support. Finally, a good carer already has a strong sense of coherence and is able and willing to receive information and support.

To conclude, the professional role of family care advisors is constructed as a delicate balance between the personal and the professional – a professional friendship within rather vague boundaries where family carers sometimes need to be educated in order to maintain the difficult balance.
When the family care advisors construct their professional role, they also construct family carers, which includes implicit moral notions of a ‘good carer’. Being aware of implicit notions and the consequences of seemingly ‘innocent’ ways to describe and categorize professionals and clients is important because categorical work includes implicit moral notions and expectations. To understand how professionals construct themselves and their clients strengthens knowledge, awareness and the practices of social work by helping to avoid the reproduction of normative notions. The increased societal emphasis on family caregiving and the development of family carers as clients need to take this into consideration. Further research is needed to gain more knowledge about the interaction between family care advisors and family carers, including the balancing act of professional friendship. It is also relevant to study further the consequences of making family carers into clients.

Acknowledgments

The author wishes to express her gratitude to the participants in the research circle for sharing their experiences with her.

Disclosure statement

No potential conflict of interest was reported by the author(s).

ORCID

Åsa Alftberg http://orcid.org/0000-0002-1447-6478

References


