Communicative Care in Online Forums:
How Burdened Informal Caregivers Seek Mediated Social Support

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Health care in aging societies increasingly demands that relatives, partners, or friends provide informal care for loved ones at their end of life. Yet, being an informal caregiver involves significant health threats caused by so-called caregiver burden. To cope with the broad spectrum of challenges, informal caregivers seek social support in the care relationship network emerging around a (future) patient. However, obtaining social support is not limited to offline contexts. Members of online communities also provide experiential knowledge and social support. To explore how informal caregivers seek and provide social support online and how this is interrelated with their care relationship networks, we conducted a qualitative content analysis of 75 threads about advance care planning from German online forums (2003–2017). Our findings show that informal caregivers rely on what we conclusively coined *communicative care* (i.e., informational and emotional support in burdensome care situations), often in response to impaired offline relationships within care relationship networks.

Keywords: advance care planning, caregiver burden, care relationship network, communicative care, distrust, health care, informal care, online communities, qualitative content analysis, social support

Developments in aging societies suggest that the need for long-term and end-of-life care will increase significantly over the next decades, posing challenges not only to professional medical care but also to the *informal care* provided to loved ones by their partners, relatives, and friends in various social arrangements (Broese van Groenou & De Boer, 2016). In 2010, across the Organization for Economic Co-operation and Development countries, one in 10 adults over the age of 50 provided informal care (Colombo, Llena-Nozal, Mercier, & Tjadens, 2011, p. 13), and according to a study published by the European Commission in 2018, 23% of the adult German population provided informal care at least once a week

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(Zigante, 2018, p. 19). However, the need for informal care as a supplement or even substitute for professional care will continue to increase because of longer life expectancies, life-prolonging medical treatments, and elderly illnesses, such as dementia (Conrad, 2005; Hiel et al., 2015). As the World Health Organization (2012) estimates, the number of patients with dementia alone will almost triple worldwide to 152 million by the year 2050. The same trend applies to Germany, where the number of patients with dementia, currently 1.7 million, will grow to approximately 3 million in 2050 (Sütterlin, Hoßmann, & Klingholz, 2011).

But dementia is not the only reason patients might rely on informal care. Currently, approximately 4.7 million people in Germany require care, and toward this end, 6.9% of German adults (4–5 million) substitute for professional care by acting as informal caregivers, two thirds of whom assume this role two or more hours per day (Wetzstein, Rommel, & Lange, 2016, pp. 3–4). In the German health system, informal care constitutes unpaid work, and it can thereby serve as financial relief for a health system under economic pressure. In other words: "The legislator makes the fundamental assumption here that care is provided by family and friends on a voluntary basis" (Wetzstein et al., 2016, p. 2).

The Experience of Caregiver Burden

Aside from its problematic economic implications, the mostly unpaid work of informal caregivers can affect their health and well-being, especially for women, who are responsible for providing two thirds of informal care. One half of those who provide at least two hours of care per day report that because of their care duties, their general state of health is "not good," and that their own everyday activities are limited or adversely impacted. In addition, approximately 20% of these caregivers report feeling severely mentally stressed (Wetzstein et al., 2016, p. 6).

These data illustrate that extensive informal care becomes eminently life-altering for all involved when patients lose their physical or mental autonomy. A major problem is that informal caregivers usually "do not have any formal training, nor do they have the skills or necessary experience to handle such an endeavor" (Alpert & Womble, 2015, p. 714). Even though gratifying experiences have been reported, the most common concept in the literature is that of *caregiver burden*, that is, mental and physical exhaustion and health problems caused by giving lay care (Bauer & Sousa-Poza, 2015; Hayes, Hawthorne, Farhall, O'Hanlon, & Harvey, 2015; Penning & Wu, 2016). Research shows that informal care can lead to social isolation and often has a negative impact on the caregiver's quality of life (Hayes et al., 2015). Most informal care experiences are characterized by mental, physical, and financial strains, moral and social conflicts, and decision-making dilemmas, which render becoming an informal caregiver not only a burdensome responsibility, but actually a health threat (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Bastawrous, 2013; Carretero, Garcés, Ródenas, & Sanjosé, 2009).

Those distressing facets demonstrate that informal caregivers not only provide care, but are often themselves in need of care. Caregiving is mainly regarded as a mental health threat comprising emotional stress, exhaustion, and depression, which at the same time correlates with less time for sleep and exercise (Alpert & Womble, 2015; Penning & Wu, 2016). Hence, being a reliable provider of informal care is as much about maintaining the caregiver's health as it is about the care receiver's health outcomes. The problem is

that informal caregivers are often reluctant to disclose their caregiving burden to health professionals. When German informal caregivers were asked about their motives for providing care, 92.6% emphasized their emotional bond with the patient, and 85.8% stressed their sense of duty (Eurofamcare Consortium, 2006, p. 136). These responses indicate that the motives of these informal caregivers intersect, creating an emotional obligation that represents the social norm of solidarity (Broese van Groenou & De Boer, 2016, p. 276). However, this norm cultivates the misconception that the concerns and distress of caregivers must be endured in silence and should not be considered before the needs of the care receivers (Ramirez, Addington-Hall, & Richards, 1998, p. 209).

Informal care and caregiver burden have thus far received little attention in health communication. One of the few comprehensive studies that have taken a health communication approach was recently published by Jeong, Kim, and Chon (2018). In their literature review, the authors conclude that "there is a lack of research examining how caregivers cope with this situation in their daily life" (p. 5), especially with regard to the use of various communication channels, including cyberspace. In a survey of 104 participants from South Korea, the active information-seeking behaviors of informal caregivers and their effect on coping outcomes were investigated. The results underline the importance of what the authors coined *cybercoping*, showing that "caregivers' active information-seeking behavior in cyberspace is essential for the process of dealing with their patients' health problems," while forwarding information to others by posting comments and sharing personal experiences "is also essential for the process of managing emotional and psychological issues of caregivers through online social support" (Jeong et al., 2018, p. 11).

Before we go into detail on the health benefits that online social support might offer, we further outline the social arrangements in which informal caregivers coordinate their care.

Embedment in Care Relationship Networks

We now theorize a specific constellation in which many informal caregivers find themselves. Therefore, we situate informal caregivers in what we coin *care relationship networks* (CRNs). Such networks consist of numerous lay, as well as professional, actors and their relationships for the purpose of providing care to a care receiver. In line with Gottlieb and Bergen (2010), we argue that it is essential to acknowledge this social arrangement to apply a "sensitive and comprehensive inquiry into social support" (p. 512). Our CRN concept is grounded in the premise of "relationship-centered care," which is built on four principles developed by Beach, Inui, and the Relationship-Centered Care Research Network (2006, p. 3): (1) Relationships in health care ought to include the personhood of the participants; (2) affect and emotion are important components of these relationships; (3) all health care relationships occur in the context of reciprocal influence; and (4) the formation and maintenance of genuine relationships in health care are morally valuable.

Against this backdrop, we argue that relationship-centered care primarily comprises the communication between the actors in a CRN, such as the patient, informal caregivers, and health or legal professionals. Consequently, care is not limited to medical care for the patient, but can also include caring communication between all actors who need social support and around whom their own CRNs form that become active when required (see Figure 1).
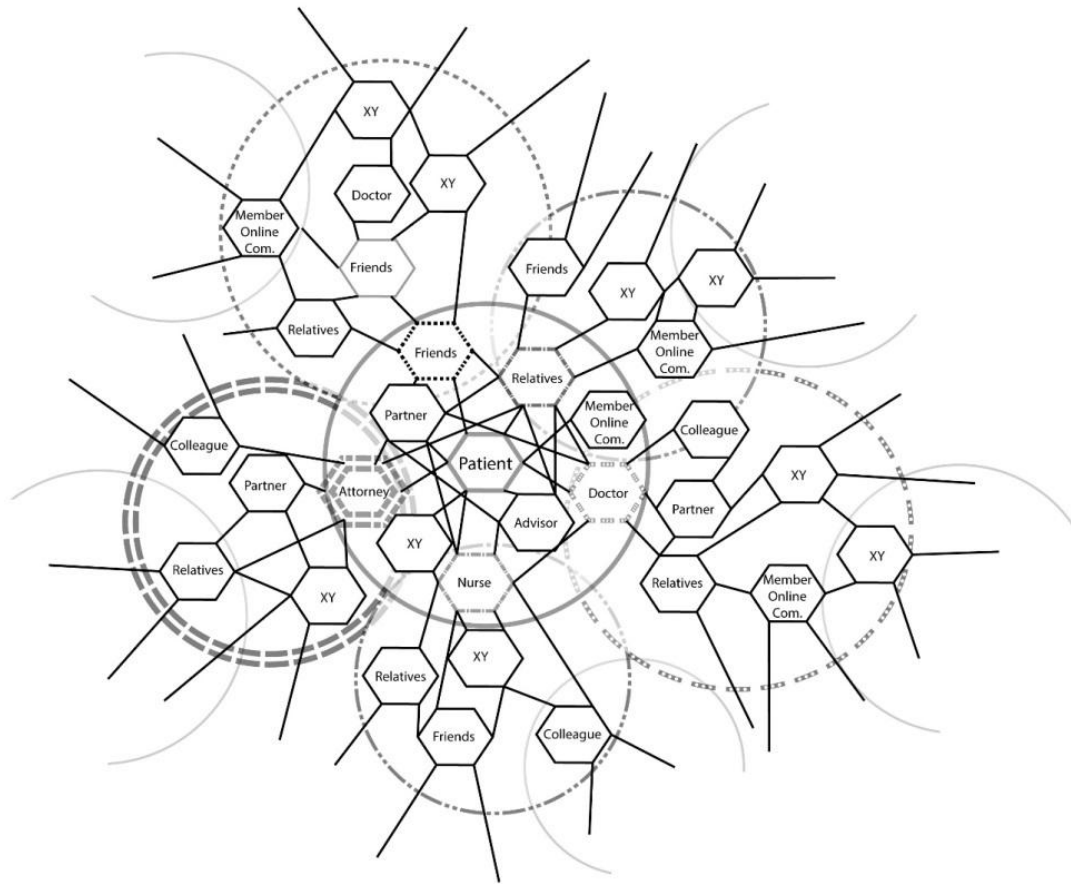
Figure 1. Theoretical illustration of CRNs.

Hence, to study the challenges informal caregivers face, it is important to empirically identify their ties to, and their communication with, other actors in the network, as well as the quality of their relationships. This shift in perspective acknowledges that care is not something directed only at the patient, but that often-overlooked actors, such as informal caregivers, can also become recipients of care when needing support.

The Context of Advance Care Planning

These outlined CRNs rarely form spontaneously but rather evolve throughout the process of planning ahead or in the course of a recently diagnosed illness. One scenario in which CRNs form and are negotiated is during *advance care planning* (ACP), which is "the process whereby patients, in consultation with healthcare professionals, family members and other loved ones, make individual decisions about their future healthcare, to prepare for future medical treatment decisions" (Houben, Spruit, Groenen, Wouters, & Janssen, 2014, p. 1). In many countries, including Germany, ACP documents, such as advance directives

or health care proxies, have been introduced into the health system so that care receivers can formulate their own will or wishes in advance to prevent ethical and practical conflicts in future medical decision making (Simon, 2014). However, ACP is not limited to filing legal documents but describes the process of communicatively determining the care receiver's will. Therefore, certain roles and tasks are assigned to specific actors, who consequently constitute a CRN (Houben et al., 2014, pp. 1–2).

Once the patient enters the anticipated medical state, the CRN acts on the verbal and formal agreements established during ACP. Here, the respective actors perform the predefined roles, such as that of informal caregiver, preferably in accordance with all other CRN members. Even though each actor might have different responsibilities, objectives, and health care assessments, they are nonetheless all connected to the task of caring for a patient's needs, around which they organize their actions (Beach et al., 2006; Romer & Hammes, 2004).

The problem is that many patients do not engage in ACP at all or only when their health condition is expected to worsen in the foreseeable future. One key indicator is the slow spread of advance directives. Even though an upward trend is evident, a representative survey from 2017 showed that 57% of Germans did not have an advance directive, and that only 32% of those had thought about preparing one in the future. Even more problematic is that 23% were not even planning to prepare an advance directive, and 8% had never even heard of its existence (Deutscher Hospiz- und PalliativVerband e.V., 2017). As Brauer (2017) points out, the major reason for not engaging in ACP is that topics of death and illness are typically not discussed in everyday life so long as individuals and their social circles are fairly healthy. This usually changes when one or one's loved ones face an existential health crisis that motivates the establishment of an advance directive. Hence, advance directives are "embedded in discourses of fear and notions of pain" (Brauer, 2017, p. 5), which makes engaging in ACP a challenging task at any stage of life.

In the course of ACP, there are several potential reasons for caregiver burden: In case arrangements and documents are set up, potentially burdensome ethical and emotional decisions with loved ones about care responsibilities and the limits of care and medical treatments have to be discussed. Once a patient actually experiences the loss of autonomy, two common—yet not exclusive—subsequent scenarios often occur: (1) Either informal caregivers try to realize the arrangement and care tasks agreed on during the ACP and experience this as burdensome or (2) a loved one that suddenly became a patient never engaged in ACP, which means that the CRN emerges rather spontaneously depending on the circumstances and without the patient's documented will. Besides demanding care tasks, informal caregivers are then confronted with the uncertainty of decision making without knowing the patient's will. In these scenarios, online forums about ACP can become an access point for informal caregivers who seek social support to cope with caregiver burden apart from their offline CRN.

(Dis)trust in Care Relationships

Why, however, would an informal caregiver turn to online social support? One reason might be conflicts and distrust in offline CRNs. Trust is essential to the establishment and development of care relationships in CRNs because, as Hall, Dugan, Zheng, and Mishra (2001) put it, trust is "inseparable from *vulnerability*, in that there is no need for trust in the absence of vulnerability" (p. 615). Consequently, trust

is pivotal to CRNs, as they are particularly concerned with vulnerability resulting from a high degree of (anticipated) dependency in asymmetrical end-of-life relationships (Rowe & Calnan, 2006).

We follow an understanding of trust that highlights the importance of relationality and emotional bonds (Fan, Lederman, Smith, & Shanton, 2014, p. 534) and applied it to our conception of CRNs. This allowed us to emphasize that communication aimed at facilitating good care depends on and, at the same time, requires trust as a vital element for creating and maintaining functioning CRNs. A convincing concept of trust based on this notion is presented by Carnevale and Wechsler (1992), who identified the following main features:

> Faith or confidence in the intentions or actions of a person or group, the expectation of ethical, fair, and nonthreatening behavior, and concern for the rights of others in exchange relationships. Trust also involves a willingness to place oneself in some jeopardy, to risk vulnerability, to take the chance that one's dependency will not be exploited. . . . The development of trust in a relationship is reciprocal, so that individuals respond in kind to the trust or mistrust directed toward them. (p. 473)

In the literature on health care, trust is considered important for many reasons, such as encouraging the use of health care services, facilitating positive health outcomes, cultivating an openness to communicate personal medical information, and reinforcing a general commitment to maintaining care relationships (Gilson, 2006, p. 361; Hall et al., 2001, p. 630). Communication is not only critical to establishing trust, but also allows for the exchange of comfort, support, and intimacy, which together strengthen emotional bonds.

Hence, distrust between informal caregivers and care receivers, physicians, and other members of a CRN affects not only ACP, but also where and to whom one turns to cope with caregiver burden. Distrust may be rooted in one's personal history with the care receiver or in conflicts with other family members regarding decision making or care responsibilities, or one might in general distrust the health care system and health care professionals, causing reluctance to seek professional assistance and instead motivating the search for online social support (Abelson, Miller, & Giacomini, 2009, p. 64; Seale, 2003).

Beneficial Health Communication: Seeking and Providing Social Support Online

Whereas research on health communication among informal caregivers is scarce, literature and data on the role of online communication in coping with health-related issues are abundant. From early on, *social support* as a concept has been divided into different subcategories with various qualities. The two main subcategories are *informational* and *emotional support*. Under informational support, Cutrona and Suhr (1992, p. 161) include suggestions and advice, the referral to other sources of help, appraisals of the situation, and the provision of detailed information to teach the other how to deal with the problem at hand. Emotional support entails stressing the importance of the emotional bond in a care relationship, giving (physical) affection, assuring confidentiality, expressing sympathy for a person's situation, listening to their problems, being empathetic, and encouraging them to provide hope and confidence.

The benefits of social support are evident for both mental and physical health (e.g., Cohen & Syme, 1985; Doull, O'Connor, Welch, Tugwell, & Wells, 2017). Studies have found that social support can "reduce psychological distress" and "promote psychological adjustments to chronically stressful conditions" (Taylor, 2011, p. 191), a familiar situation for informal caregivers. Furthermore, Taylor (2011) emphasizes in his broad literature review that, to be beneficial, the social support a social network provides must be "appropriate for meeting the stressor" and must "come from the right person" (p. 194). These results stress that social support is beneficial in many regards, but the question remains: What changes in online environments?

Social media allow access to the experiential knowledge of others, as well as to social support from people with similar health-related experiences that can rarely be obtained from health professionals (Beck, Paskewitz, Anderson, Bourdeaux, & Currie-Mueller, 2017; Braithwaite, Waldron, & Finn, 1999; Tanis, 2008). According to the Pew Research Center's Health Online 2013 survey, 59% of Americans searched for health information online in the past year, 26% of whom read about someone else's health-related experience, and 16% sought out others with the same health concerns (Fox & Duggan, 2013). Such peer-to-peer support is also evident in Germany, as a survey from 2018 revealed that 46% of Germans searched for online health information in the past year, among whom 30% searched for related experiences of others concerning health-related issues, and 16% sought emotional support (Marstedt, 2018, pp. 10–13). As Jeong et al. (2018) show, informal caregivers are among those whose coping mechanisms include seeking information and support in cyberspace.

Following Kim and Grunig (2011), when informal caregivers are faced with a problem they feel they must resolve, they might be motivated to choose online forums for two reasons: First, the benefits outlined by Fan et al. (2014) create the expectation "that information matches their subjective life problems" (Kim & Grunig, 2011, p. 122). Second, for some, online forums provide instrumental and purposeful "heightened communicative activeness" (Kim & Grunig, 2011, p. 124) that is facilitated by the reciprocity of communication inherent to online social support networks and focused on the resolution of problems. One such problem, we would argue, might be caregiver burden.

White and Dorman (2001) found that online social support has unique benefits compared with face-to-face conversations, such as easily locating others who share the same health care-related problems; asynchronous communication, which allows extended response time; anonymity, which permits the discussion of sensitive topics; and universal access at (almost) any time or place, which is particularly important for people with limited mobility or restricted time resources (e.g., informal caregivers with care responsibilities; p. 694). Furthermore, the authors highlight the risks of misinterpreted communication caused by a lack of nonverbal and contextual cues, false information, or unqualified advice from nonprofessional users (White & Dorman, 2001, p. 695). In general, social support is regarded as effective online as offline when it emerges in online communities that discursively establish valued care relationships based on perceived familiarity, similarity, and empathy that create the necessary environment to foster trust among the members (Fan et al., 2014, pp. 539–540). Subsequently, informal caregivers can find social support online because of genuine empathy, firsthand experiential knowledge, and a sense of connectedness, all of which are difficult for health professionals to provide (Fan et al., 2014, p. 532).

Considering our discussion of the foregoing research, a question emerges as to how social support is actually communicated online in the context of ACP, caregiver burden, and the quality of relationships in CRNs.

Consequently, we investigated three research questions in the context of informal caregiving and ACP:

RQ1:   *How do informal caregivers seek and provide informational and emotional support in online communication?*

RQ2:   *What defines relationships established online between informal caregivers seeking social support and those who can provide it?*

RQ3:   *How is seeking social support related to distrust and conflicts in offline care relationships in CRNs?*
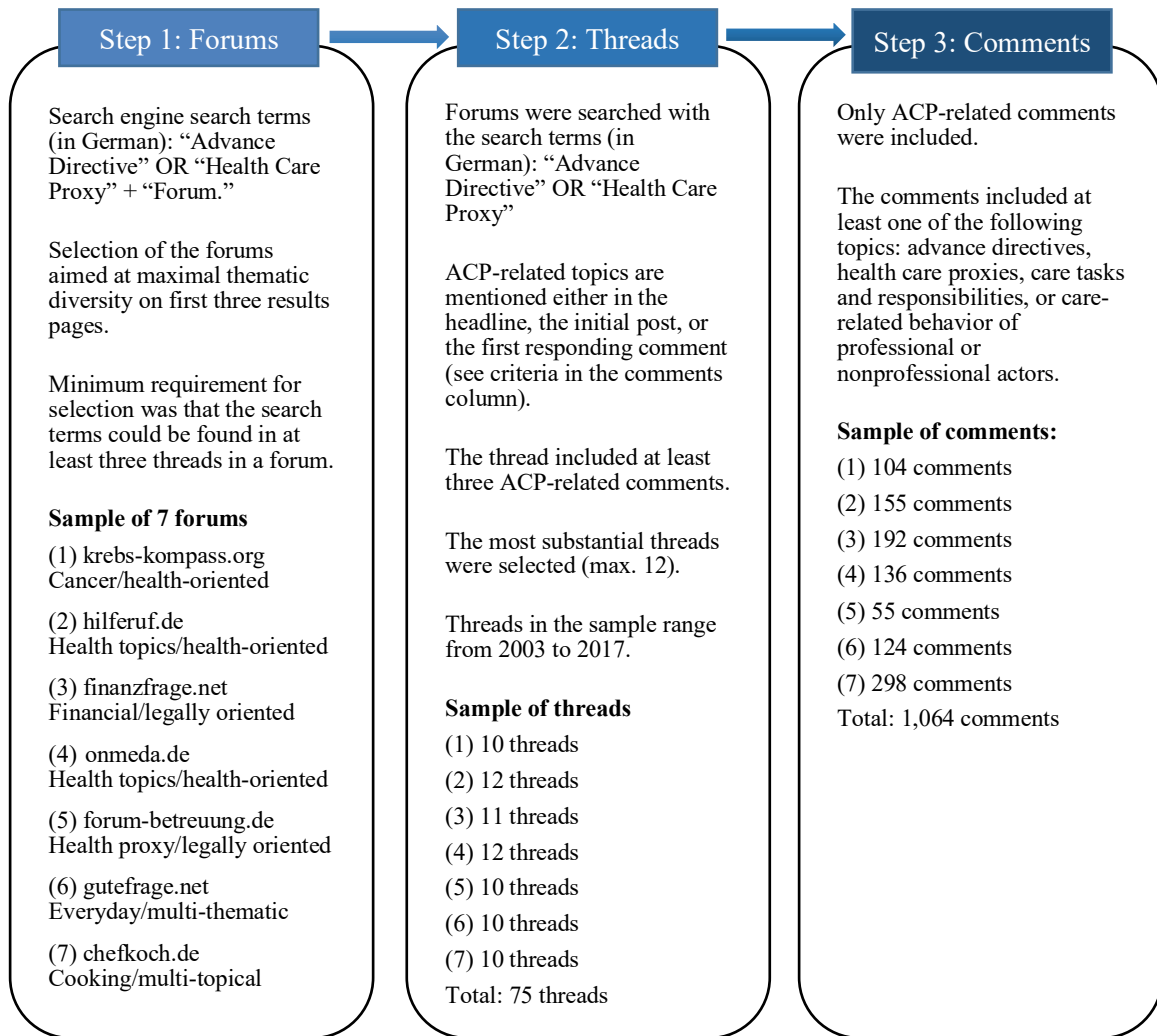
Method

In our study, we aimed to complement the insights generated by Jeong et al. (2018) through survey data by investigating the actual content posted online by informal caregivers. To answer the posed research questions, we conducted a directed qualitative content analysis of comments in 75 threads related to ACP and health care documents from seven German online forums in which informal caregivers share their experiences of planning and carrying out informal care as well as disclose the challenges they confront regarding care tasks and relationship conflicts in the CRN. As Hsieh and Shannon (2005, pp. 1281–1283) stress, a directed qualitative content analysis mainly draws from preceding theories and research on a given topic to develop a coding scheme and answer research questions. Such a qualitative approach does not aim to quantify the research material by deploying statistical analysis, but instead seeks to interpret essential and typical themes or patterns in order to understand relationships between phenomena and the contexts in which they manifest, such as the nexus of caregiver burden, CRNs, ACP, and online social support (Hsieh & Shannon, 2005, p. 1278). Hence, the aim of qualitative research (i.e., our analysis) is not representativity but generalizability.

Sampling Strategy

For our study, we selected online forums that included threads related to ACP. As we have outlined in detail, ACP is a process that allows one to understand the constitution of CRNs as well as the challenges that informal caregivers face once they are confronted with care tasks at a care receiver's end of life. During end-of-life care, informal caregivers experience extremely challenging mental and physical circumstances that might culminate in caregiver burden. These aspects make ACP a sufficient thematic context for our research regarding online social support.

The sample was drawn in three steps to identify the most relevant online forums for ACP discussions (see Figure 2 for details).

Step 1: Forums	Step 2: Threads	Step 3: Comments
Search engine search terms (in German): "Advance Directive" OR "Health Care Proxy" + "Forum."	Forums were searched with the search terms (in German): "Advance Directive" OR "Health Care Proxy"	Only ACP-related comments were included.
Selection of the forums aimed at maximal thematic diversity on first three results pages.	ACP-related topics are mentioned either in the headline, the initial post, or the first responding comment (see criteria in the comments column).	The comments included at least one of the following topics: advance directives, health care proxies, care tasks and responsibilities, or care-related behavior of professional or nonprofessional actors.
Minimum requirement for selection was that the search terms could be found in at least three threads in a forum.	The thread included at least three ACP-related comments.	
Sample of 7 forums	The most substantial threads were selected (max. 12).	**Sample of comments:**
(1) krebs-kompass.org Cancer/health-oriented	Threads in the sample range from 2003 to 2017.	(1) 104 comments
(2) hilferuf.de Health topics/health-oriented		(2) 155 comments
(3) finanzfrage.net Financial/legally oriented	**Sample of threads**	(3) 192 comments
(4) onmeda.de Health topics/health-oriented	(1) 10 threads	(4) 136 comments
(5) forum-betreuung.de Health proxy/legally oriented	(2) 12 threads	(5) 55 comments
(6) gutefrage.net Everyday/multi-thematic	(3) 11 threads	(6) 124 comments
(7) chefkoch.de Cooking/multi-topical	(4) 12 threads	(7) 298 comments
	(5) 10 threads	Total: 1,064 comments
	(6) 10 threads	
	(7) 10 threads	
	Total: 75 threads	

Figure 2. Three-step sampling process. ACP = advance care planning.

In the first step, Google was used to search for *advance directive* OR *health care proxy* AND *forum*. This strategy was chosen because research has shown that 77% of those who search for health-related issues online start by using a search engine (Fox & Duggan, 2013, p. 3). The seven selected forums were chosen from the first three results pages and with the aim of maximum diversity, as the search revealed that discussions of ACP are not restricted to health-oriented forums alone (e.g., forums on cooking, finances, and daily life issues also include ACP-related discussions). This indicates that as a topic, ACP emerges in communities in which members feel comfortable sharing their thoughts and experiences, regardless of the original topical focus of the forum. The chosen forums are hosted by advertising- and service-based forum providers. Whereas "krebs-kompass," "forum-betreuung," or "hilferuf" mainly offer forum functions using a reduced, outdated design and are not listed in official user statistics, "gutefrage" and "finanzfrage" belong to

the same domain (47 million visits in November 2019) and include several subforums provided by a professional company in a modern fashion. "Onmeda" (8.9 million visits in November 2019) and "chefkoch" (89 million visits in November 2019) are also quite popular, and they additionally provide service content; in the case of "onmeda," articles on health topics and expert opinions are included, and "chefkoch" offers recipes, articles, and videos (Informationsgemeinschaft zur Feststellung der Verbreitung von Werbeträgern, 2019).

Once the forums were chosen, another search for the topics *advance directive* OR *health care proxy* was conducted to identify the 10 to 12 most relevant and interactive threads in terms of topical fit and number of responses. To be included, the initial post or first reply had to mention at least one of the following topics: advance directives, health care proxies, care tasks and responsibilities, or the care-related behavior of professional or nonprofessional actors. The same selection criteria were applied to other comments posted in the thread. Following this procedure, the sample included the seven most relevant forums in terms of the search results ranking, topical fit, the extent of user interactivity, and the depth of the comments. The final sample comprised 75 threads from 2003 to 2017, with a total of 1,064 comments. We translated comments cited in the analysis from German to English.

Coding Scheme and Coding Process

The coding scheme was developed deductively from the theory and was complemented by inductive codes drawn from the material (Hsieh & Shannon, 2005). The material was subjected to coding to identify themes and patterns in the comments concerning descriptions of CRNs, caregiver burden, and informational as well as emotional support. According to Fan et al. (2014), online communication is discursive, subjective, and experiential. Thus, the discursive dynamics among comments were considered, as they create the relationality and reciprocity necessary for social support. Four main categories drawn from the theory, extended by further subcategories drawn from both the theory and the material, guided the analysis:

1. CRN

Following Beach et al. (2006), care relationships are based on respecting the personhood of participants, their reciprocal influence on each other, and the emotional quality of relationships as anchored in beliefs about their moral value. Should conflicts arise and trust be replaced by distrust, then the ability of the CRN to support participants might be adversely affected (Carnevale & Wechsler, 1992; Romer & Hammes, 2004). To capture the state of a CRN from the perspective of forum members, we coded the category CRN whenever individuals outlined the constellation of their CRN in their communication. The descriptions' subcategories included (1.1) the actors, (1.2) their care roles, their (1.3) potential or (1.4) limitation to offer social support, and the quality of the care relationship, that is, if it was represented as (1.5) harmonious or (1.6) conflictual.

2. Caregiver Burden

As discussed in the literature review, caregiver burden is experienced when care is mentally and physically challenging and subsequently affects one's health (Adelman et al., 2014; Bastawrous, 2013; Carretero et al., 2009)**.** When individuals disclosed burdensome experiences resulting from their roles as

informal caregivers, this was coded as caregiver burden. This entailed subcategories with (2.1) descriptions of situations and (2.2) conflicts experienced as stressful and demanding, as well as the explicit mentioning of (2.3) mental or (2.4) physical health issues related to informal caregiving, and (2.5) confusion or anxiety about care tasks.

3. Informational Support

Informational support is based on experiential knowledge gained through personal care experiences that empower an individual to facilitate problem solving by providing useful, relevant information (Beck et al., 2017; Taylor, 2011; White & Dorman, 2001). Hence, this category was coded when forum members responded to each other with information they had gathered from their informal care work. The subcategories included different types of experiential knowledge, such as (3.1) advice about where to find further help or (3.2) specific medical or (3.3) legal information. Furthermore, advice on (3.4) how to practically deal with difficult health care situations and care tasks was coded as a subcategory.

4. Emotional Support

Emotional support is less about practical problem solving and more about being empathic and providing both comfort and confidence (Beck et al., 2017; Cutrona & Suhr, 1992; White & Dorman, 2001). Emotional support was coded when members reacted with empathy by communicating concern for another person's situation and emotional well-being. The category also included subcategories regarding (4.1) the efforts to provide comfort and encouragement to another person to help them cope with their emotional distress. Emotional support also entailed (4.2) stressing the shared care relationship and (4.3) the value of supporting each other.

To ensure the quality of coding in qualitative content analysis, we cannot rely on reliability tests usually conducted in quantitative research because the codes are not used to translate text into numerals, but rather to structure the material for abstraction and subsequent interpretation. Therefore, the quality of coding is determined by the trustworthiness of the data organization. As suggested by Elo et al. (2014), we used the following procedure to ensure trustworthiness: The material was coded by one researcher, after which a second researcher reviewed "the whole analysis process and categorization" (p. 5) and then resolved divergent coding choices and conflicting interpretations with the first researcher. Hence, the analysis was based on finding common ground in terms of coding and interpretation.

The coding followed a three-step process. First, each coder read the material to obtain an overview of the themes in the posts. Then, using the QDA software *f4analyse*, the main categories drawn from the literature were coded. Simultaneously, subcategories were introduced when new themes emerged in the material that the literature did not include beforehand. After this step, the two coders compared their sets of categories, discussed their divergent choices and interpretations, and subsequently combined their categories into one final coding scheme. Finally, the material was coded once more with the abovementioned coding scheme.

Results

Theme 1: Caregiver Burden Is Not a Precondition to Seek Informational Support

Seeking social support does not necessarily originate from caregiver burden. In our analysis, informal caregivers often searched only for information about ACP in the process of organizing documents for their loved ones who were not (yet) in need of comprehensive care. Even though informal caregivers may find this phase difficult and confusing to some extent, it does not seem to cause caregiver burden, as described in the literature; hence, these posts did not mention stress or exhaustion. Instead, the communication indicated that the informal caregivers were not yet familiar with the topic and started threads with numerous questions about basic aspects about which they were anxious, such as where to find documents, how to formulate one's will, and who to talk to about the medical or legal aspects of ACP:

> Which health care proxies and directives should my mother prepare? She is terminally ill with intestinal cancer. What would you recommend? Did you use pre-printed forms or did you ask an attorney for advice? I also read that an advance directive has to be hand-written. Is it true? Did you get it certified by a notary? (krebs-kompass.de, 2007)

In these cases, the community was often addressed to confirm or disprove superficial knowledge based on the members' experiential knowledge. Most important, emotional support was not provided in these threads because the questions were information-oriented and little emotional distress was shared. These members were in the phase of anticipation and were not yet affected by caregiver burden; thus, there was little need for emotional support.

Theme 2: Caregiver Burden Especially Motivates Emotional Support Seeking

The situation changes when informal caregivers experienced circumstances that demanded more mental and physical resources from them. In this scenario, relatives, partners, and friends of the patient not only seek informational, but also emotional support online. A typical case is that of a member who explained that her father was in an artificial coma and it was unclear who he intended to be his proxy. Due to insufficient ACP, the family had to decide who should become the proxy because, otherwise, a professional proxy would be assigned. She turned to the community for advice and emotional support:

> My family assumes that I will become the proxy. On one hand, I want the best for my dad and I do not want to abandon him. On the other hand, I do not really think I am capable to do it. My head is spinning. Does anyone of you have experiences with being a proxy? (hilferuf.de, 2016)

The responses that followed conveyed concern, but were also encouraging. They addressed both the problems outlined and the emotional burden of the member searching for social support:

> It is understandable that you are overwhelmed by this situation. That being the case, you
> should take good care of yourself and not let others pressure you into something that you
> can't handle. (hilferuf.de, 2016)

The communication between the members underlines the element of empowerment aimed at enabling informal caregivers to solve the situation. As this example illustrates, former informal caregivers address the danger of caregiver burden, warning others to be mindful of their own health and limits.

Theme 3: Experiential Knowledge Is Key to Empathy, Trust, and Social Support

Many comments show two things in particular: Social support based on experiential knowledge is considered authentic and creates familiarity and that emotional support, in particular, strengthens the bond between the support provider and the receiver:

> Thank you again for your comment, I actually was in tears. It seems you know exactly
> what you are writing about.

> Reply: It was not my intention to make you cry because there are plenty of reasons to cry
> in such a situation. Yes, I know exactly what I am talking about and I wanted to encourage
> you. Please take good care of yourself in the times ahead. (onmedia.de, 2008)

In such cases, the usual pattern is that others try to share their experiential knowledge of similar conflicts in CRNs to help informal caregivers cope with the emotionally demanding circumstances. This was usually done in a very encouraging and friendly tone, and in return, the receiver expressed gratefulness. Thus, care relationships were established in which some members became regularly addressed providers of social support:

> Hello and thank you for your support. It is really nice of you to care so much about us.
> This makes me really happy.

> Reply: I am also very happy that you replied to me. I enjoy writing to you because from
> what I have seen it is not easy for you. All the best for both of you, it is great how you
> are holding up. (krebskompass.de, 2011)

Much appreciation was shown in the conversations, particularly for those who engaged in conversations even though they were no longer in need of social support themselves: "Thank you that after all you are still active in the forum" (onmedia.de, 2015) or "I would like to really thank all of you. Your answers helped me and my mother a lot! I knew that I could rely on you!" (chefkoch.de, 2010). Typically, those who gave such advice had been informal caregivers in the past. They had already been active in CRNs, know about the challenges, and feel obliged to support others going through similar experiences. They provide the communities' stock of knowledge, which enables them to not only give emotional support but also to help with information gained during firsthand experiences with ACP and informal care.

Theme 4: Distrust and Conflicts in CRNs Motivate Seeking Social Support Online

Negative experiences during caregiving and distrust in care relationships often motivated informal caregivers to seek social support outside their offline CRN. Many mentioned negative experiences with relatives or other CRN members:

> Everybody only wanted the best for him—unfortunately, everybody thought they knew dad better than the others. And my mother had yet another opinion about it. There was a lot of potential for disputes that could have been prevented or at least minimized with advance care. (chefkoch.de, 2011)

Comments like this one stress how ACP is not only about the patient's will but also about preventing conflict in CRNs by anticipating responsibilities and decision making beforehand. If a CRN lacks such a basis, the likelihood of conflict increases and subsequently limits the potential for social support among affected relatives and friends. Instead of reducing caregiver burden through social support within the CRN, conflicts aggravate the situation:

> When my mother got ill with breast cancer the first time in the late 90s I asked her if she had thought about a power of attorney or a living will. I was misunderstood and accused back then. My sister even accused me of legacy hunting. . . . Then cancer came back in 2007. Again, nothing happened. Even when it was clear that my mother was going to die, my sister did not support me. (krebskompass.de, 2010)

In many comments, the members described conflicts in CRNs that they could not resolve by themselves and subsequently shared them online to seek social support.

Theme 5: Distrust Goes Beyond Personal Care Relationships

The excerpts of often lengthy and detailed stories we just quoted show that those informal caregivers either did not trust their relatives with decision making or, even more profound, distrusted their character and integrity. Such descriptions of negative experiences indicate that unsolved conflicts create distrust in the existing offline care relationships, leading to a burdensome situation that threatens CRN cohesion. In the online community, informal caregivers asked for help to either restore trust in impaired offline care relationships or to cope with a situation they had not been able to solve cooperatively in the CRN.

However, conflict and distrust in CRNs are not limited to relatives and friends, but also include professional actors as representatives of health care or legal institutions. In some cases, a general distrust of, and vigorous skepticism about, certain institutions becomes evident:

> Sickness is an economic factor—it (has become) a business! And when somebody wants to do business he will try to follow certain goals. If an advance directive is an obstacle to these goals, what do you think will happen? (krebskompass.de, 2009)

Institutional distrust seems to translate into care relationships in CRNs, particularly fostering prejudices about the intentions of physicians and legally appointed proxies. It was assumed that both try to benefit financially from patients, placing their own interests first, and therefore cannot be trusted: "What is interesting is that doctors don't even try to save your life but first and foremost want to fill their own pockets" (hilferuf.de, 2014). Such comments seem to reflect fears that not only result from firsthand personal experiences, but also from public debates about health care scandals. Criticism in the comments sometimes referred to media coverage used as evidence for the appropriateness of distrust:

> A health care proxy is worth nothing these days, as I have seen in several TV programs about care and nursing homes. . . . I was shocked because elderlies were put into nursing homes against their own or their relatives' will. (chefkoch.de, 2011)

Nevertheless, the informal caregivers who distrusted relatives, friends, or professionals from certain institutions also argued that health care proxies and advance directives can be considered a way to protect loved ones from CRN actors who are not perceived as trustworthy: "It is not only about trust but about a strong will and the strength to assert oneself against doctors, nursing homes and public authorities" (gutefrage.net, 2011). This contradicts what ACP is originally supposed to achieve, which is collaborative and continuous communication among patients, informal caregivers, and professionals to support each other in the best possible way. Consequently, a number of members challenged such negative or even false accounts by stressing the integrity of the majority of health care and legal professionals.

Conclusively, the analysis shows that a lack of trust in care relationships, actors, and institutions motivated informal caregivers to extend their CRNs online to seek social support from members in online communities they consider more reliable and trustworthy.

Discussion

Informal caregiving is a challenging task, and one that will become increasingly important in the following decades. Without denying the existence of joyful moments, the overall experience is often immensely burdensome. Further substantiating the research of Jeong et al. (2018), our study indicates that caregiver burden motivates individuals to seek mediated social support. However, Jeong et al. focused more on information seeking and forwarding behavior and less on the individuals seeking emotional support, a dimension that was central to our study. However, regarding information seeking, we found that informal caregivers followed a rather rational and practical approach to problem solving as described by Kim and Grunig (2011). Confronted with uncertainty about how to proceed with ACP and advance directives, informal caregivers often turned to online forums to obtain the information needed to solve their problems (i.e., who to contact, where to find forms, and how to complete them). Our approach was limited to online forums, which consequently prevented us from knowing whether the information posted on the forums was implemented in CRNs at some point.

In our study, however, the informal caregivers described rather intimate relationships with their loved ones in the comments they made in their CRNs. Hence, emotional distress and (dis)trust in relationships were far more prominent topics than they were in the study by Jeong et al. (2018). In line

with the findings of Penning and Wu (2016), comments made by informal caregivers demonstrated that their emotional involvement especially amplified their feelings of distress and their experience of caregiver burden, which in turn fostered the need for emotional support. The value of their online relationships seemed to be particularly important, mostly based on the status of some members as "experiential experts," as Tanis (2008, p. 699) calls them. Based on their experiential knowledge, (former) informal caregivers provided social support that current caregivers perceived as coming "from the right person" (Taylor, 2011, p. 194), thereby cultivating empathy, familiarity, and trust (Fan et al., 2014, pp. 539–540), all of which represent important preconditions for the acceptance and efficiency of both informational and emotional support (Cohen & Syme, 1985).

It was only due to the discursive nature of online forums, as described by Fan et al. (2014), that such valued relationships could be built. The reciprocal communication in which members engaged allowed them to express gratitude for the social support they received. These expressions conveyed subjective experiences of improvement concerning caregiver burden. Based on our analysis, this sense of improvement can be attributed to aspects outlined by Taylor (2011) and Fan et al. (2014), such as a reduction in feelings of distress facilitated by the communicative sharing of past and present caregiver burden as well as experiences of empowerment in handling such burden after receiving social support. The results demonstrate that informal caregivers seem to experience health benefits from online social support similar to those experienced by patients with specific (mental) illnesses that have thus far constituted the epicenter of attention in health communication research (e.g., Braithwaite et al., 1999; Tanis, 2008; White & Dorman, 2001).

Regarding different patterns as expressed in the forums, we were only able to identify dissimilarities with respect to how members sough information: The more specific the forum's thematic scope, the more specific the questions asked. Questions about financial issues were more prevalent in the "finanzfrage" forum, and inquiries about cancer were predominant in the "krebs-forum." However, the ways in which emotional support was given after informal caregivers shared their burden were similar, expressing empathy and trust. Turning to such forums appears to constitute a productive alternative for coping with caregiver burden when informal caregivers are not comfortable with disclosing their situation to health professionals (Ramirez et al., 1998); that said, these forums certainly should not replace the guidance, instruction, and counsel of trained health professionals.

In our analysis, we demonstrated that one reason for seeking social support online and not from health professionals or close social circles is rooted in deficits in existing CRNs. Negative experiences of conflict, a lack of successful communication, and distrust in relatives and friends as well as in health care professionals, as described by Abelson et al. (2009), Hall et al. (2001), and Beach et al. (2006), are common reasons why informal caregivers turn to online forums. When the care relationships between certain CRN actors are impaired, informal caregivers would rather share their burden with trusted peers. However, in some cases, the social support received online seemed to have helped informal caregivers repair their offline relationships and find solutions to conflicts.

In combination with their friendly and empathic tone, online communities often evoke a level of trust that permits members to transcend informational support and receive emotional support, subsequently

enacting what we conclusively coin *communicative care*. With this term, we stress that informal caregivers not only provide care but, due to caregiver burden, require care. Compared with the patient for whom they care, informal caregivers require communicative care, not medical care, to cope with the responsibilities and challenges they face in their role.

At the same time, this realization highlights an important limitation of our study: Via our qualitative content analysis, we were able to answer our research questions about how informal caregivers seek and provide social support online, what defines their online relationships, and how these factors are related to their offline CRNs by investigating their actual communications. And yet, considering that informal caregivers typically communicate in anonymous media environments, we were unable to determine who they were in terms of their socioeconomic status, gender, or other demographic and personal characteristics. To connect our insights from the communicative content with the individuals providing informal care, it is imperative to conduct further research.

Conclusion

Our findings demonstrate, using the example of ACP and end-of-life care, that informal care is not an individual but rather a social task of caregiving. Consequently, it must be conceptualized and investigated with approaches sensitive to the importance of networked care relationships. Doing so permits a shift in attention to the informational and emotional needs of all involved actors in a CRN instead of limiting the focus solely on the medical needs of the patient. The presented study sheds light on actors whose significance for care might not be evident at first glance; yet, these actors are experiencing challenging circumstances in which they rely on communicative care, either in their CRN or online. Therefore, the results highlight the benefits of online social support for these actors, while emphasizing the significance of establishing online care relationships as a substantial augmentation of CRNs.

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