Constructing expertise in digital dementia support groups: The CODEx model

Carolin Schneider Ward[1]

Birte Bös[1]

NAME OF DEPARTMENTS AND INSTITUTIONS:

[1] University of Duisburg-Essen, Germany

CORRESPONDING AUTHOR:

Carolin Schneider Ward. Email: carolin.schneiderward@uni-due.de.

QHC Qualitative Health Communication

ABSTRACT

Background: Social media have become an important arena for health-related discourse. As neurocognitive diseases such as dementia become more prominent, digital spaces increasingly serve as sites where knowledge is shared and expertise is constructed and negotiated among individuals living with dementia, care partners, and medical staff. **Aim:** This paper proposes the Construction of Online Dementia Expertise (CODEx) model to capture the collaborative formation of expertise based on a multifaceted body of knowledge in dementia-related online support groups. **Methods:** The CODEx model builds on findings from previous empirical studies of two datasets, a message board for individuals living with dementia and a care partners' support group, which were investigated through the lenses of interpersonal pragmatics and mediated discourse analysis. **Results:** The CODEx model illustrates how dementia-related expertise emerges through iterative, interactive processes that transcend the boundaries between online and offline contexts. In the discursive space of online support groups, users impart explicit propositional knowledge and articulate tacit experiential and procedural knowledge. **Discussion:** The CODEx model helps to explore the diverse social roles and knowledge facets discursively constructed in dementia-related online support groups which prototypically rests on personal experience as a central source of knowledge. **Conclusion:** The CODEx model provides a framework for understanding the complex discursive co-construction of expertise in dementia-related online support groups and has potential applications in other areas of mediated health discourse.

KEYWORDS

BIOGRAPHIES

Carolin Schneider Ward is a postdoctoral researcher in English Linguistics at the University of Duisburg-Essen. Her research focuses on (digital) health communication and multilingualism, with an emphasis on discourses with and about dementia. Her publications include *An Ethno-social Approach to Code-Choice and Code-Switching in bilinguals living with Alzheimer's* (2023) and several peer-reviewed articles as well as a special issue co-edited with Birte Bös on *Dementia in Social Media Discourse* (2026).

E-mail: carolin.schneiderward@uni-due.de. ORCiD: 0000-0003-4282-1213.

Birte Bös is Professor of English Linguistics at the University of Duisburg-Essen, Germany. Her research interests include synchronic and diachronic pragmatics, discourse analysis and media linguistics. She has investigated the communicative practices in historical and modern media. Together with Carolin Schneider Ward, Birte has published several papers exploring discourses with and about dementia. She has co-edited several books and special issues, e.g. *Discourse, Context & Media*, Special issue: *Dementia in Social Media Discourse and Digital Interaction* (2026).

E-mail: birte.boes@uni-due.de. ORCiD: 0000-0002-1328-0828.

Introduction

In the past fifteen years, social media have become an important environment for the negotiation of health-related issues among laypersons and professionals, and the digitally mediated practices involved have attracted a range of linguistic studies (cf. e.g. the special issue on language and health online edited by Kleinke, 2015; Locher & Thurnherr, 2017; see also section 2). As the aging population is increasingly affected by neurocognitive diseases like the dementias, it is hardly surprising that this has become a much-discussed topic in the social media, too.

In online support groups frequented by individuals living with dementia, care partners and medical staff, the collaborative construction of collective knowledge and expertise feature as a core element. Based on results from prior research on dementia-related online support groups (Bös & Schneider, 2019, 2021, 2022a, 2025; Schneider, 2025; Schneider & Bös, 2019, 2024) we aim to develop a model which carves out the complex, dynamic nature of expertise in these settings.

The Construction of Online Dementia Expertise (CODEx) model rests on analyses of two main datasets: 28 threads from a dementia message board which is mainly frequented by individuals living with dementia and 27 threads from an online support group for care partners (see section 3). Data triangulation and a qualitative approach grounded in interpersonal pragmatics (cf. Davis, 2010; Locher & Graham, 2010) reveal the diverse perspectives of stakeholders in dementia-related digital discourse, which are integrated into our model.

The CODEx model, introduced and illustrated in section 4, captures how constructions of expertise are fueled by both users' online experiences in the respective support groups and their offline experiences. It shows how different resources of expertise, whether explicit propositional or tacit procedural and experiential knowledge, are mobilized, contested, and redefined in discourse, offering insights into the negotiation of participation rights, epistemic authority and the boundaries of knowledge in mediated health discourses.

Literature review

Defining expertise and knowledge

Expertise and knowledge have long been the focus of extensive research across a wide range of disciplines, resulting in diverse conceptualizations. Following Cianciolo and Sternberg (2018), we take an ecological perspective on expertise, viewing it as "everyday expert performance in a range of settings" and assuming

> that everyday experts are capable of achieving the right fit between their abilities and the demands of a situation, and that the development of expert performance, whether demonstrated in such everyday feats as reading and writing or in exceptional accomplishment, reflects the outcome of people's engagement in the world around them (Cianciolo & Sternberg, 2018, p. 770).

Expertise can thus be developed in various domains (including the dementia context in focus here) and is situated in time and place (including diverse offline and online spaces). Furthermore, expertise can be understood as a continuum, ranging "from the

complete ignoramus through a novice, trainee to a full expert or even a master" (Hetmański, 2018, p. 13).

Expertise rests on different kinds of knowledge and skills, as well as the social roles attributed to those who possess it (Bourne et al., 2014, p. 1; Hetmański, 2018, p. 11). Based on Ryle's classic differentiation of 'knowing that' and 'knowing how' (2009[1949]), expertise is often conceptualized as consisting of propositional (codified, scientific) knowledge, which is explicit, as well as procedural knowledge and experiential knowledge, which is often tacit (Eraut, 2000; Hetmański, 2018). Broadening the "concept of academic and occupational expertise" (Cianciolo & Sternberg, 2018, p. 784), the notion of tacit knowledge is particularly insightful in the context of lay expertise, which plays a central role in the CODEx model. As posited in the theory of practical intelligence,

> the development and application of tacit knowledge, a critical aspect of success in everyday life, occurs through a practically intelligent cycle of inquiry, knowing, and action, that is, a cycle of engaging the environment, acquiring tacit knowledge, and using it to perform" (Cianciolo & Sternberg, 2018, p. 771).

In that respect, tacit knowledge is essentially experiential, though it is also closely linked to the notion of procedural knowledge. However, tacit experiential knowledge is seen as more adaptive in complex novel situations, while procedural knowledge essentially involves routine responses that become automatic through consistent exposure to familiar patterns or tasks (Cianciolo & Sternberg, 2018, p. 773).

While tacit knowledge has often been conceptualized as difficult if not impossible to articulate, scholars such as Nonaka & Takeuchi (1995: 62) have pointed out the possibility of converting tacit knowledge, either from tacit to tacit through processes of socialization or from tacit to explicit through externalization (see also Tee & Karney 2010: 387). That tacit knowledge can transition into explicit knowledge and thus contribute to the development of expertise is particularly relevant in the context of digital dementia discourses, where individuals verbalize and share their experiences in their Communities of Practice (Cianciolo & Sternberg, 2018, p. 770f., see also Tee & Karney, 2010). Indeed, these processes could be frequently observed in the digital Communities of Practice (CofP) investigated in our studies.

Already back in 2012, Panahi et al. recognized the potential of collaborative social media formats "where a community of specialized practitioners can share, critique and validate their collective experiential knowledge" (2012, p. 1095). Based on a review of existing studies, they found that the sharing of tacit knowledge is positively associated with five key features of social media that support this process: fostering social interaction; enabling experience sharing (e.g. through storytelling); facilitating informal relationships and networking; allowing observation (e.g. of shared multimedia content); and promoting mutual understanding and trust (Panahi et al., 2012).

Social media as a site of health communication

Social media has become a central resource for individuals seeking health information, offering access to a wide range of perspectives, advice, and support that extends beyond traditional medical settings. One key reason people turn to social media for health information is the sense of connection and community it provides.

Digital platforms allow individuals to share and affirm their experiences with others, creating spaces where users feel supported and less isolated. This is especially important for individuals whose health conditions, such as dementia, limit their ability to participate in public or social life – often due to both internal and external stigma associated with the illness and its progression (Dimitrov et al., 2022, Petersen et al., 2020). The same is true for informal care partners, e.g. family members of people living with dementia (Sillence, 2017).

Online forums for care partners and increasingly also for individuals living with dementia themselves have emerged as digital CofPs where knowledge, solidarity, and identity are co-constructed through interaction. These digital spaces are characterized by a delicate balance between emotional proximity and protective distance. Users share intimate personal stories, offer empathic validation, and engage in collective reflection, yet they also maintain boundaries, balancing how much of themselves they reveal (Bös & Schneider, 2021, 2022a, 2025; Schneider, 2025). The asynchronous, semi-anonymous nature of forums allows for both vulnerability and control, creating an environment where users can be emotionally open without overexposing themselves.

Across these spaces, users frequently challenge the reductive narrative that defines dementia solely through loss. Instead, many speak of living with rather than suffering from the condition (cf. Bös & Schneider, 2022b). This shift reframes the experience around resilience, adaptation, and continued individuality – not only for those providing care, but also for those receiving it (Bös & Schneider, 2021, 2022a; Kleinke, 2022).The use of metaphors, for instance, reveals how individuals living with the condition actively reshape mass media framings, drawing on source domains like war, machine, or game (instead of the widespread thief, killer or zombie metaphors) to communicate their changing realities (Pleyer, 2025).

Yet, themes and positions also vary depending on platform design, group composition and cultural context, as indicated by a comparison of UK and German forums (Kleinke & Bös, 2022). Furthermore, multimodal platforms sometimes reveal mismatches between caregiver questions and responses, and show that people living with dementia often stress themes of autonomy and dignity that may be overlooked by others. Yet, these misalignments highlight the dialogic nature of peer support, prompting ongoing clarification and more responsive care (Davis et al, 2022).

Taken together, these findings show that online peer support in the context of dementia is more than a digital extension of offline help. It is a central space of coping, shared sense-making and (re)negotiation in which participants collaboratively (re-)shape what it means to live with and care for dementia, each in their respective communities.

Expertise in digital health discourse

While traditional medical encounters are marked by epistemic asymmetries, online support groups typically feature peer-to-peer interaction of laypersons. Navigating such participatory discursive spaces requires users to assess the trustworthiness of the content and its sources. Expertise thus plays a crucial role in such online health

environments, as it underpins essential functions such as advising others and disseminating information.

Most of the users of online support groups are not "credentialed experts" (Rabeharisoa et al., 2013, p. 4), yet individuals still either perceive themselves as knowledgeable or are seen by others as credible, trustworthy, and reliable sources (DeCapua & Dunham, 1993, p. 519; Sillence, 2017). This means that expertise is not preassigned, static or absolute, but a co-constructed and relational construct, evolving through communication and contextual positioning (Rudolf Von Rohr et al., 2019), as shown in research on various health-related digital CofPs (e.g. Schneider, 2025; De Choudhoury & De, 2014; De Cock & Figuera-Bates, 2023).

In their co-construction of expertise, the members of online support groups draw particularly on experiential knowledge, which – as defined in section 2.1 – is understood as holistic, subjective, and situated in daily life, contrasting with the specialized, systematic nature of professional medical knowledge (De Cock & Figueras Bates, 2023, pp. 2–3). While experiential knowledge has gained legitimacy and prominence as a form of cultural capital in these settings, questions around who has the authority to share and define such knowledge have become increasingly important (Blume, 2017, p. 10).

Previous studies have identified a variety of linguistic and discursive strategies as key to constructing and performing expertise in online health discourse. These include referencing external sources, invoking one's professional background, citing statistics, showing empathy, incorporating humor, and sharing personal stories (Rudolf Von Rohr et al., 2019, p. 219). These strategies serve diverse communicative functions: they assert authority, foster trust, and build interpersonal connection. For example, speakers may use address terms or self-reference to assert status, while demonstrating knowledge through jargon, offering step-by-step advice, or sharing evaluations and experiences (e.g. Locher, 2006).

While prior research has provided valuable insights into the strategies used to perform expertise, less attention has been paid to the content and composition of that expertise itself: what it consists of, and which facets are being enacted when such strategies are used. Attempts to locate the resources of peer expertise in digital health communication have led to classifications such as those by Htait et al. (2024, p. 135) who identify three types of expertise based on forum interaction: (1) personal expertise tied to lived experience, (2) community or veteran status interpreted as collective knowledge, and (3) broad-topic expertise reflecting accumulated informational resources. Vydiswaran and Reddy (2019) developed coding systems to identify peer experts in health forums based on metrics such as individual user activity and use of context-relevant keywords.

While these classifications offer valuable insights, they tend to simplify the inherently dynamic and multilayered nature of expertise. In peer-to-peer contexts – especially in emotionally charged, experience-driven contexts like dementia – expertise is fluid and continually negotiated within specific social and situational contexts. The CODEx model aims to capture these dynamics.

Data and methodology

Our model is based on analyses of two primary datasets, drawn from two online support forums: one for care partners of people living with dementia (Care Partner Board, CPB) and one for individuals living with dementia themselves (Dementia Message Board, DxB). Research on digital discourse – especially when it involves data produced by vulnerable groups as in our case – inevitably raises ethical tensions that requires careful, case-based considerations (franzke et al 2020; Markham & Buchanan 2017). Accordingly, we approach research ethics as "a contextualized process of decision-making" (Tagg & Spilioti 2022: 91), attentive to the situated risks and expectations shaping our research context.

Our research design was reviewed by the ethics committee of the Faculty of Humanities (University of Duisburg-Essen). Moderators were informed about the research, as requested by the community guidelines, and the researchers did not actively participate in any discussions. All data was pseudonymized, identifying details such as timestamps, locations, or device references were removed, and we verified that backtracking of individual comments was not possible. An overview of the datasets is provided in Table 1.

Table 1. *Overview of dataset.*

Digital Support Group – Care Partners (CPB)	Dementia Message Board – People living with Dementia (DxB)
27 original posts + comments ca 20,000 words	28 original posts + comments ca 78,000 words

The CPB subset comprises 27 threads from a formerly public online support group (which since ceased to exist in its past form and function) with over 28,000 members, designed for care partners of individuals living with dementia (see Bös & Schneider, 2021). DxB is hosted by a national Alzheimer's organization and explicitly designated for individuals living with dementia (see Bös & Schneider 2022a, 2025). The dataset consists of 558 posts in total, including 28 thread-initiating posts and 530 comments.

Figure 1. *User groups in the two datasets.*
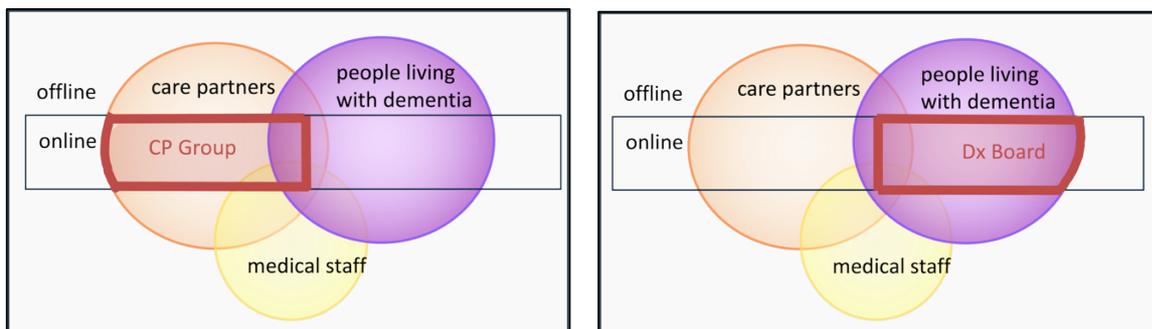
Both datasets represent dedicated digital spaces for their respective user groups. However, as reflected in Figure 1, we observe notable overlap in participation, reflecting a heterogeneity of user groups also observed in other studies (cf. Johnson et al., 2020): Individuals living with dementia sometimes contribute to the CPB, while care partners occasionally post on the DxB, often seeking direct, 'authentic' advice. These instances are particularly relevant for understanding how participation rights and

epistemic authority, and the attribution or denial of expertise are negotiated within and across groups.

Typically, users are brought together by their shared life situation of living with or caring for a person living with dementia. This gives the groups clear common goals, which include sharing their experiences and knowledge and supporting each other. Many of the users participate regularly and the threads display a high degree of interactivity. All this, we argue, gives rise to digital CofPs (see Bös & Schneider 2021, p. 89, 2022a, p. 214; cf. also Leuckert & Leuckert, 2020).

In order to illuminate the different domains of expertise and facets of knowledge mapped out in the CODEx model, we draw on examples from both datasets, preserving users' original spelling. They are marked by CPB (Care Partner Board) or DxB (Dementia Board) to indicate their source.

The CODEx model

Modelling the construction of dementia expertise in digital CofP

Expertise, as we understand it, is a multidimensional, co-constructed concept. The CODEx model presented in Fig. 2 aims to capture this complexity by bringing together interdisciplinary conceptualizations of expertise (cf. Section 2.1) and insights from our previous research on digitally mediated discourse in the dementia context (Bös & Schneider, 2021, 2022a, 2022b, 2025; Schneider, 2025; Schneider & Bös, 2019, 2024). It visualizes the processual, interactive nature of the construction of online dementia expertise, showing the three major parties involved: people living with dementia (purple circle), care partners (orange circle) and medical staff (yellow circle). In order to understand the resources for the construction of dementia-related expertise we need to consider multilayered communicative situations where boundaries between online and offline contexts are not fixed, but continuously transcended in dynamic, circular processes. Likewise, there might be overlaps in the social roles of the participants.

Figure 2. *The CODEx model: Facets of knowledge in the dynamic co-construction of online dementia expertise.*
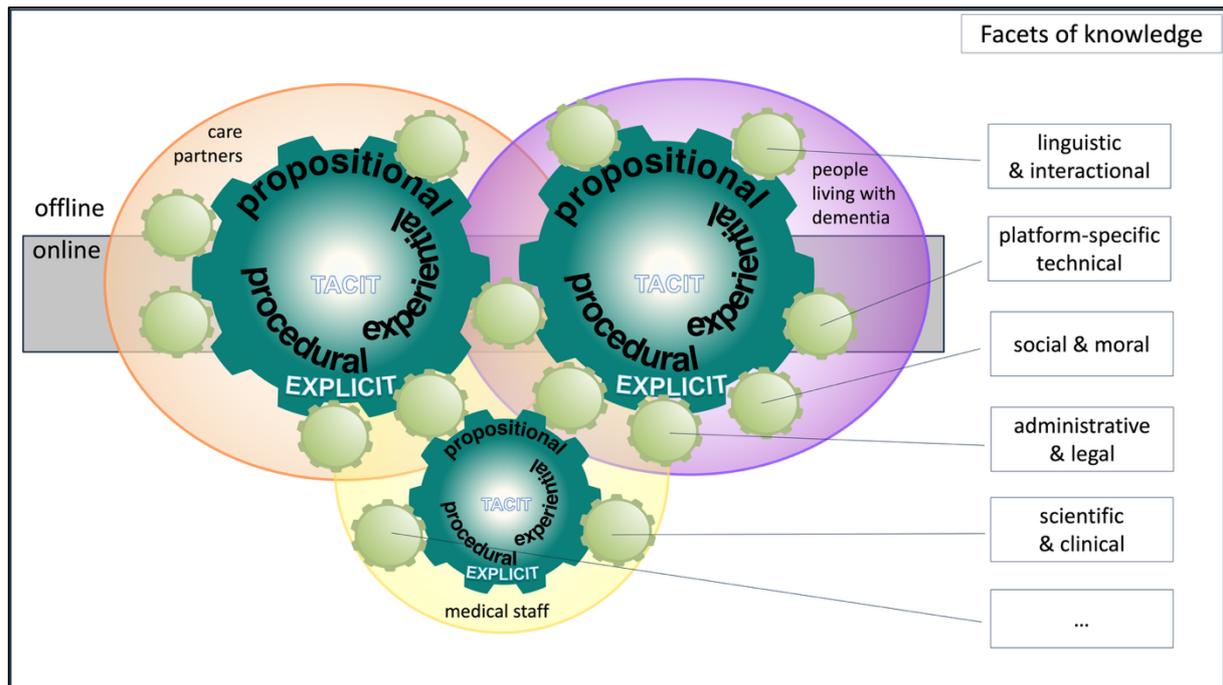
The model is conceived as a system of interlocking gearwheels. The three larger gears represent the knowledge that members of the three groups bring with them: highly individual arrays of propositional, procedural and experiential knowledge, much of which is tacit in nature. Yet, as discussed above, not just codified propositional knowledge, but also tacit knowledge resting on lived experiences can be made explicit both in offline encounters and in the digital CofPs in focus here. These manifestations of different kinds of knowledge in discourse are symbolized by the smaller surrounding gears in the model. They include a broad range of knowledge facets, from platform-specific technical knowledge to administrative and legal, scientific and clinical, cognitive and psychological, social and moral, linguistic and interactional knowledge, and more.

Our on-screen data from the two digital support groups thus shed light on the discursive manifestations of knowledge facets, the development of collective knowledge and the construction and negotiation of expertise in these arenas. They surface in narrative expressions of lived experiences, metapragmatic reflections on offline interactions as well as on the relational dynamics within the online support groups themselves, advice-giving and referencing practices, the use of scientific language, etc. (see section 2.3). The makeup of our data comprises people living with a form of dementia as well as care partners who are interacting on both selected boards, where positing practices, for instance through sharing experiences, facilitate the exchange of knowledge (e.g. see Bös & Schneider 2025).

Insights shared in the online group may directly influence practices offline, which in turn shape future contributions and forms of knowledge brought back into the digital space. This reciprocal flow reinforces the notion that dementia-related expertise is not confined to a single sphere but is co-constructed across settings. The interweaving of personal and professional experiences, scientific information, practical application and social interaction creates a feedback loop through which knowledge is

continuously (re)negotiated, constructed, and recontextualized. In this way, lay expertise and professional expertise are connected, complemented by the social media expertise required for participation in digital CofPs. Drawing on examples from our previous studies, sections 4.2 to 4.4 will further elaborate these domains of expertise.

Digital context: Social media expertise

As the digital context provides the discourse arena, the degree of participants' digital literacy skills in general and platform- and community-specific knowledge in particular has an impact on the construction and negotiation of dementia-related expertise. Both digital and dementia-related expertise can be aligned (e.g. when a person newly diagnosed or starting to care for someone living with the condition enters a previously unfamiliar platform/support group); however, this is not necessarily always the case.

Our data provides evidence of different degrees of familiarity with platform- and community-specific kinds of knowledge, including knowledge about the sociotechnical affordances, about linguistic preferences, and social and interactional norms of the groups.

Platform infrastructure is taken up in comments by new members to the group who encounter technological barriers or unmet expectations, e.g. by asking for help in editing their own posts (1).

(1) (DxB-RE01/03) Do u know if we can " copy and paste" or "cut and paste" in the postings? I havnt been able to do that....

Yet, comments on technicalities are also linked to the specific needs of users living with dementia, thus highlighting the intersection between technical affordances and dementia-related aspects. For example, certain features of platform design might be particularly obstructive for users living with dementia, but also generally affect the usability and potentially accessibility of these digital spaces (2).

(2) (DxB-R15/03) And then there are technical problems with the website that make it difficult to use even for people without dementia. This is just my pet peeve, but could the banner ad selling the caregiver notebook be removed.

Likewise, a spell check might certainly be useful in many online environments, yet the user in (3) expresses their need in the context of "typing with dementia" (see Bös & Schneider, 2022a).

(3) (DxB-OP01) I sure wish this website has spell check! LOL

In reaction, the user in (4) provides instruction on how to find the spell check, thus demonstrating a higher level of platform-specific technical knowledge.

(4) (DxB-R01/01) Look at the top of the text area where you see 'B' 'I' and 'U'. Next is ABC 'check'. That is the spellcheck. Do you see it?

Some platforms signal peer expertise through visible metrics, such as participation frequency or peer validation via profile labels or user signatures (De Cock & Figueras Bates, 2023, p. 6). However, such quantifications tend to prioritize engagement over content knowledge, potentially obscuring more nuanced forms of expertise. For example, the care partner in (5) self-identifies as "[b]eing new" both to the CPB and

the dementia context. Based on the lack of previous expertise in a particular digital context, Vydiswaran and Reddy (2019) refer to such newcomers as novice users.

(5)   (CPB-P23/23) Being new here and screaming out for support i have several questions

However, technical, social, and experiential dimensions may not always align neatly and, group novices may still possess substantial experiential or professional dementia knowledge, even if they are not (yet) familiar with the platform's architecture.

Another key facet of platform-/community-specific knowledge is knowledge about the linguistic conventions on the platform, register and sociolinguistic awareness and accommodation skills (cf. e.g. De Choudhury & De, 2014; Leuckert & Leuckert, 2020). In the context of our data, this involves particularly an awareness of language use that supports cognitively accessible communication.

On dementia-specific forums, users frequently reflect on how their own writing may impact others with cognitive impairments, providing insights into emergent sets of community-specific language norms shaped by concern for readability and inclusion. This includes deliberate efforts to minimize ambiguity, e.g. through careful spelling (6).

(6)   (DxB-OP01) So now i feel i hav a healthy balance by leaving in minor typos that people can still figure out what i typed. However ive tried to type "perfectly" in posts on this website sinc we all hav cognitive deficienes. [...]

Still, it might require prolonged engagement to develop an understanding of community-specific linguistic practices, e.g. the use of group-specific abbreviations (7).

(7)   (DxB-R24/14) I didn't know a lot of these abbreviations when I joined this board

Furthermore, example (8) points at the necessity to account for different linguistic backgrounds and levels of language skills which may affect the clarity and pragmatic appropriateness of contributions, and it reveals strong group-specific social norms and expectations, which constitute another knowledge facet.

(8)   (CPB-P09/OP) I'm shocked and appalled that many of you jumped on the young man who posted recently about the miraculous recovery of his father's memory.

Clearly English is not his first language and his expression of his joy that his father responded to new medications was taken literally by several people who felt that he was trying to scam or mislead the members of this group [...]

Support groups such as those in focus here are characterized by specific sets of social and interactional norms, values and expectations (cf. Angouri, 2015). These are partly expressed explicitly in FAQ and community guidelines, but most importantly, they evolve and manifest through ongoing online interactions, where they are also explicitly debated by participants (cf. Kleinke & Bös, 2015).

As indicated in Figure 1 above, the support groups explicitly cater for users living with dementia (DxB) or their care partners (CPB). However, the digital spaces are also frequented by a lower number of members of the respective other group and some medical professionals. In both DxB and CPB, participation rights and norms of appropriateness are metapragmatically negotiated (9, 10), particularly when

participants feel that they are not acknowledged as experts in their own cause or that their space is invaded (Bös & Schneider 2022a, p. 226; cf. Craig & Strivens, 2016, p. 50).

(9) (DxB-RE16/08) Some of us patients do not appreciate hearing how "horrific" others feel the disease is and such type of language on a patient board can be frightening.

(10) (DxB-RE02/03) I am truly sorry that your life is so difficult right now. However, it is our right to express our joy as well as, our woes and struggles on this board

Occasionally, these negotiations give rise to open conflicts between users living with dementia and care partners. In (11) an experienced user on DxB takes over a mediating role and reminds their fellow participants of the core values of support and mutual respect, expanding the well-established journey metaphor also found on CPB:

(11) (DxB RE03/19) We are all people just traveling this journey. We may be in different lanes but we are all headed in the same direction, on the same road. It's like traveling and stopping to ask for directions. Sometimes the directions are clear, other times not so much. May we all just be open to giving and receiving directions. Peace.

What it is that users share and how they share is subject to previous experiences in digital spaces in general and in these support groups in particular. Ex (12) displays extracts from the lengthy discussion triggered by comment (8) above, relating to the contribution by and reactions to a linguistically less versed L2-user on CPB.

(12) (CPB-P09/R8) People keep mentioning about this guy's FB profile. I don't know why that makes a difference. I, for one, am not big on sharing about my dad's dementia on FB or any personal medical illness. I only share on this page. Just because he doesn't have a picture of his dad doesn't make him a bad person.
(CPB-P09/R16) Well said R8 I'm the same
(CPB-P09/ R17) Amen!
(CPB-P09/R18) ... and may we all pray for those who were cruel and so quick to judge ...
(CPB-P09/R19) Thank you and well said. All you haters.....please remember we are all going through our own hell and don't need your individual judgement. Either be nice or shut up....more negativity is not needed in this group

The users' interaction displays typical group-specific practices, such as a high frequency of prayers and expressive speech acts, as well as explicit negotiations of group norms and expectations, e.g. questions of authentication and degrees of self-disclosure, participation rights and boundaries, behavioral and affective norms including the group's preference for positivity, non-judgment and emotional safety. Incidentally, the safe environment strived for in both support groups facilitates the co-construction of knowledge, particularly tacit knowledge, which "is best shared and cultivated in a climate of love, care, trust, and commitment" (Tee & Karney, 2010, p. 409).

Dementia context: Lay expertise

Online support groups offer a prototypical setting for the emergence and recognition of lay expertise, where personal experience is a central source of knowledge and

authority. Yet, as shown in the CODEx model, lay expertise does not only rest on experiential and procedural knowledge gained through dealing with their own or others' situations, but also propositional knowledge acquired in self-directed research (based on academic studies, popularised medical discourse, patient guides, etc) and interactions with medical staff.

Users' claim to knowledge and expertise often rests on explicit self-references highlighting their social roles (e.g. full time carer for my mom). While users typically foreground one particular social role, there is also evidence of users grounding their comprehensive knowledge and expertise in multiple roles. In (13), the user introduces themself to various newcomers in DxB, self-positioning as an expert based on professional status (physician), expertise from both sides of the care dyad (care recipient – care partner in various constellations), as well as expertise as a long-term member of this particular digital CofP.

> (13) (DxB RE03/21) I know what I am talking about. I have extensive experience as a physician caring for the ill and the gravely ill. I have been a personal care partner for my Mom, and a distant caregiver for other family members. I have had years of experience as a care recipient with several difficult to manage medical conditions, dealing with family care partners and professional caregivers. And I have been on this board for seven years, learning from fellow patients and from wonderful caregivers.

Ingroup construction as digital CofPs of lay experts is fostered by the combined usage of self-referential labels and inclusive pronouns (e.g. we caregivers), which is quite salient in the data. A special situation arises due to the fact that dementia can potentially reduce access to the personal knowledge bases and impede participation of individuals living with the condition in offline and online interactions. Our data show that on DxB, users position themselves as experts in their own cause, also representing those in the more progressed stages who are not or no longer present in the digital sphere (14).

> (14) (DxB-R02/11) Try to remember that we, patients with dementia, who are posting here, are in early to mid stage. The caregivers who are posting here, are most likely to be caring for someone who is in the later part of mid stage to end stage. We are talking about two different sets of folks

Experienced "dementia trailblazers" (Johnson et al., 2020: 127, p. 14) such as the users in (13)-(15), take a particularly active role, fostering the distribution of scientific, procedural and experiential knowledge and supporting less experienced participants, e.g. by explicating knowledge in a Best Practices list (15).

> (15) DxB RE04/04 Are you familiar with what several of us PWD on these boards call Best Practices? Adapting these as a Life Style has the possibility of slowing down the progression of the disease. Further research has shown that adapting more than one has a multiplying effect.
>
> 1. Take meds as directed.
>
> 2. Physical exercise. The goal is to get the heart pumping, for a bit, at a faster than normal rate. Research shows this builds brain tissue.
>
> 3. Cognitive exercise. A variety is best. You want to stimulate but not frustrate.
>
> 4. Mediterranean Diet. (search on line), no smoking, limited alcohol.

> 5. Increase or maintain socialization level. we need face to face contact with others. Usually we do not like large and/or noisy groups.

Similar to activists in offline patients' organizations (cf. Rabeharisoa et al., 2013), these users take over mediating roles, providing accessible scientific information and authentic, trustworthy advice.

Yet, the most important resource of making tacit experiential and procedural knowledge explicit is through narratives which blend personal experiences with socially shared interpretation and thus do not only amplify such forms of knowledge, but contribute to collective sense-making and the co-construction of expertise. Participants position themselves as peer experts based on their experiential knowledge gained in their (mostly) daily care couple interaction, which gives them the right and, as some users might argue, also the duty to contribute their knowledge and provide advice (cf. Hedman et al., 2014, p. 12).

Experiential knowledge is complemented by acquired (and sometimes reappropriated) scientific knowledge. It is displayed in many forms, e.g. in the use of specialist language, which next to some quite technical terms and descriptions also includes abbreviations for non-technical terms (e.g. LO – 'loved one') contributing to a 'technicalization' of the discourse (16).

> (16) (CPB-P27/R17) White matter in the brain oversees communication, judgment, apathy and numerous other aspects that once lost the LO no longer possesses the ability to respond as they did in the past.

Demonstrating expertise in this way can be a means of distancing from the personal dimension of the illness, but also part of a jargon which helps increase ingroup solidarity, as it presupposes CofP-specific knowledge. Users also share direct quotes from biomedical research, references to journal articles, expert websites, podcasts, etc (17).

> (17) (DxB-RE05/26) Mark Hyman, neurlogist--his website and Podcast called tje Broken Brain are suppose to b really Good! Also hav u heard of Acuenergetics?

Equally important is the way in which this explicit knowledge is interpreted and made meaningful through relating it to the users' own lived experience. Participants thus co-construct knowledge in an ongoing negotiation between explicit scientific information and tacit, context-specific knowledge. For instance, extract (18) about PET scans illustrates how users exchange information about what such scans reveal and discuss whether newer imaging methods reduce reliance on post-mortem confirmation.

> (18) (DxB-R09/04) I am so sorry. Did you get a copy of the pet scan? [...]
> (DxB-R09/05) [...] Pet scans when positive show the progression of the disease (too well.)
> (DxB-R09/06) I don't understand what the pet scan shows. [...] But the use of the pet scans for diagnoses is new, correct? Meaning we no longer have to rely on autopsy?

Through such exchanges, theoretical knowledge is collaboratively examined and adapted to individual contexts, supporting shared sense-making and informed decision-making within the groups.

Dementia context: Professional expertise

As mentioned, the majority of participants in the two support groups draw on more or less pronounced levels of lay expertise. Yet, some users also signal professional medical expertise, for example by using self-referential labels that indicate the certified status of 'credentialed experts', such as intern, RN or cna. Similarly, references to institutional affiliation (e.g. graduate school, employment in dementia care facilities) further anchor individual claims to professional knowledge.

Still, these cases remain relatively rare, as users within the two datasets hardly ever mention potential double roles of being a healthcare professional and a family care partner or an individual living with the condition and a professional expert (but see (19) and (13) above).

> (19) (CPB-P21/R03) I been cna & caregivers all together 17 yrs.

Notably, some participants (e.g. 20) explicitly link their professional identity with their personal experience of illness, highlighting how shifting roles affect both their perceived authority and their vulnerability.

> (20) (DxB-R15/15) You mentioned being a nurse. I was an RN prior to my illness. We tend to want to heal everyone. Fix things. Take care of everyone especially our Loved Ones. [...] As a person with EOAD, I can tell you that it is very difficult loosing things. For instance, I lost my job.

At the group level, however, there is also clear distancing from professional expertise. Community guidelines of CPB include a disclaimer stating "we're not doctors," and members in both datasets collectively construct an us vs. them dynamic that sets community-based experiential expertise apart from medical expertise. This relational work is evident in how users openly challenge the competence and thoroughness of doctors, frequently recommending second opinions when they perceive diagnostic input or medical advice as inadequate (21).

> (21) (DxB-R09/06) [...] if the technique is new, I would be uneasy not having a second (or more) doctor evaluate. I have a profound lack of trust in doctors, not made better by the ineffective and disorganized treatment my mom received.

Such posts also articulate procedural knowledge and, thus, procedural expectations. In some cases, users even encourage ignoring medical instruction altogether when it conflicts with care partners' lived understanding of their person's needs (22).

> (22) (CPB-P03/R13) [...] Sometimes you just have to stand up and fight..as I know you are...for their best interest...reguardless of what the Dr's say. They are NOT GODS....even though some think they are.

While some contributions still entail unequivocal trust in medical staff, these are relatively rare compared to a broader pattern of medical skepticism or outright rejection of physicians' presumed omniscience. These critical stances reflect a broader shift toward redistributing epistemic authority, as laypersons position themselves not merely as passive recipients of professional counsel but as knowledgeable agents in their own right.

Discussion and conclusion

Expertise is a dynamic, multi-layered construct. The CODEx model offers insights into the interactive nature in which expertise is constructed by different stakeholders in dementia-related online support groups. It highlights the diverse body of knowledge – acquired and shared across offline and online contexts – that contributes to these collaborative processes.

Drawing on findings from previous empirical studies on two online support groups, one for individuals living with the condition (DxB) and one for care partners (CPB), the CODEx model captures the different knowledge facets manifesting in these digital discursive spaces. They include platform-specific technical knowledge, administrative and legal, scientific and clinical, cognitive and psychological, social and moral, linguistic and interactional knowledge, etc.

What makes these social media sites particularly valuable is that users do not only impart explicit scientific knowledge, but verbalize tacit experiential and procedural knowledge, e.g. by sharing their lived experiences in narratives and providing advice. These processes are supported by the shared norms and values of trust and mutual support collaboratively established within the two digital CofPs.

Yet, while members of both communities develop a distinct collective expertise that values tacit, experience-based knowledge, they do not always recognize the expertise of the respective other group. This becomes evident in negotiations over participation and speaking rights. Furthermore, lay expertise grounded in lived experience often stands in tension with explicit, institutional medical knowledge and professional expertise, which is frequently challenged in light of offline illness experiences and caregiving realities. These discursive dynamics reveal ongoing struggles for epistemic authority in the complex field of dementia-related expertise.

At the same time, these tensions point to untapped potential for further collaboration between stakeholders. Thus, online support groups could serve as valuable spaces for mutual engagement, offering access to tacit knowledge of members of the different communicative parties. Particularly the experiences articulated by individuals living with condition provide authentic insights into their day-to-day realities, which are often underrepresented in clinical frameworks but vital for a more holistic understanding of well-being and care in the context of dementia.

Ultimately, the CODEx model also has potential applications beyond the dementia context, providing a tool for analyzing how lay and professional expertise with their broad array of knowledge facets interact in other digitally mediated health settings.

Declarations

Funding

References

Angouri, J. (2015). Online communities and communities of practice. In A. Georgakopoulou & T. Spilioti (Eds.), *The Routledge Handbook of Language and Digital Communication* (pp. 323–338). Routledge. https://doi.org/10.4324/9781315694344

Blume, S. (2017). In search of experiential knowledge. *Innovation: The European Journal of Social Science Research, 30(1)*, 91–103. https://doi.org/10.1080/13511610.2016.1210505

Bös, B, & Schneider, C. (2019). Metapragmatic reflections on verbal interactions with Alzheimer's Dementia patients—A social media study [Abstract]. In C. Lindholm & A. Gerstenberg (Eds.), *Corpora for Language and Aging Research 4, Helsinki, Finland* (pp. 27-28). University of Helsinki. https://www.helsinki.fi/assets/drupal/2022-11/clare_book_of_abstracts_0.pdf

Bös, B., & Schneider, C. (2021). "We are all in this together" – Balancing Virtual Proximity and Distance in Online Care Partner Discussions. *Anglistik, 32*(2), 85–109. https://doi.org/10.33675/angl/2021/2/8

Bös, B., & Schneider, C. (2022a). 'Typing with dementia.': Online self-positioning of people living with dementia. *Journal of Interactional Research in Communication Disorders*, *12*(2), 212–233. https://doi.org/10.1558/jircd.20391

Bös, B., & Schneider, C. (2022b). Dementia sufferer and person living with a diagnosis of dementia: Naming practices in academia. *Age, Culture, Humanities: An Interdisciplinary Journal*, 6. https://doi.org/10.7146/ageculturehumanities.v6i.133272

Bös, B., & Schneider, C. (2025). "You have nothing to fear because we love you" – Expressing emotions in a digital Community of Practice of persons living with dementia. *Discourse, Context & Media, 66*, 100911. https://doi.org/10.1016/j.dcm.2025.100911

Bourne, L. E., Kole, J. A., & Healy, A. F. (2014). Expertise: Defined, described, explained [Opinion]. *Frontiers in Psychology, 5*. https://doi.org/10.3389/fpsyg.2014.00186

Bucholtz, M., & Hall, K. (2005). Identity and interaction: a sociocultural linguistic approach. *Discourse Studies*, *7*(4–5), 585–614. https://doi.org/10.1177/1461445605054407

Cianciolo, A. T., & Sternberg, R. J. (2018). Practical intelligence and tacit knowledge: An ecological view of expertise. In K. A. Ericsson, R. R. Hoffman, A. Kozbelt & A. M. Williams (Eds.), *The Cambridge handbook of expertise and expert performance* (2nd ed., pp. 770–792). Cambridge University Press. https://doi.org/10.1017/9781316480748.039

Craig, D., & Strivens, E. (2016). Facing the times: A young onset dementia support group: Facebook™ style: Facing the times: Young onset dementia. *Australasian Journal on Ageing*, *35*(1), 48–53. https://doi.org/10.1111/ajag.12264

Davis, B. (2010). Interpersonal issues in health discourse. In M. A. Locher & S. L. Graham (Eds.), *Interpersonal Pragmatics* (Vol. 6, pp. 381–404). De Gruyter Mouton.

Davis, B., Maclagan, M., & Pope, C. (2022). Digital outreach in online dementia discourse. *Journal of Interactional Research in Communication Disorders*, *12*(2), 185–211. https://doi.org/10.1558/jircd.22571

DeCapua, A., & Dunham, J. F. (1993). Strategies in the discourse of advice. *Journal of Pragmatics*, *20*(6), 519–531. https://doi.org/10.1016/0378-2166(93)90014-g

De Choudhury, M., & De, S. (2014). Mental Health Discourse on reddit: Self-Disclosure, Social Support, and Anonymity. *Proceedings of the International AAAI Conference on Web and Social Media*, *8*(1), 71-80. https://doi.org/10.1609/icwsm.v8i1.14526

De Cock, B. & Figueras Bates, C. (2023). Peer experts as actors for shared understanding in Spanish online health fora. In S. Bigi & M. Rossi (Eds.), *A Pragmatic Agenda for Healthcare: Fostering inclusion and active participation through shared understanding* (pp. 291-312). John Benjamins Publishing Company. https://doi.org/10.1075/pbns.338.12dec

Dimitrov, R., Jelen, A., & L'Etang, J. (2022). Taboos in health communication: Stigma, silence and voice. *Public Relations Inquiry*, *11*(1), 3–35. https://doi.org/10.1177/2046147x211067002

Eckert, P. (2006). Communities of Practice. In K. Brown (Ed.), *Encyclopedia of Language & Linguistics* (2nd ed., pp. 683–685). Elsevier. https://doi.org/10.1016/B0-08-044854-2/01276-1.

Eraut, M. (2000). Non-formal learning and tacit knowledge in professional work. *British Journal of Educational Psychology, 70*(1), 113–136. https://doi.org/10.1348/000709900158001

Franzke, A. S., Bechmann, A., Zimmer, M., Ess, C., & the Association of Internet Researchers (2020). *Internet Research: Ethical Guidelines 3.0.* https://aoir.org/reports/ethics3.pdf

Hedman, R., Hellström, I., Ternestedt, B.-M., Hansebo, G., & Norberg, A. (2014). Social positioning by people with Alzheimer's disease in a support group. *Journal of Aging Studies, 28*, 11-21. https://doi.org/10.1016/j.jaging.2013.11.003

Hetmański, M. (2018). Expert knowledge: Its structure, functions and limits. *Studia Humana, 7*(3), 11–20. https://doi.org/10.2478/sh-2018-0014.

Htait, A., Busso, L., & Grant, T. (2024). Hierarchies of power: Identifying expertise in anonymous online interactions. In N. Naik, P. Jenkins, P. Grace, L. Yang & S. Prajapat (Eds.), *Advances in computational intelligence systems* (Advances in Intelligent Systems and Computing, Vol. 1453). Springer. https://doi.org/10.1007/978-3-031-47508-5_11

Johnson, J., Black, R. W., & Hayes, G. R. (2020). Roles in the discussion: An analysis of social support in an online forum for people with dementia. *Proceedings of the ACM on Human-Computer Interaction, 4*(CSCW2), 1–30. https://doi.org/10.1145/3415198

Kleinke, S. (2015). Internetforen: Laiendiskurs Gesundheit [Internet forums: Lay discourse on health]. In A. Busch & T. Spranz-Fogasy (Eds.), *Handbuch Sprache in der Medizin* [Handbook of Language in Medicine] (pp. 405–422). De Gruyter. https://doi.org/10.1515/9783110296174-023

Kleinke, S. (2022). Constructing dementia in discourse. *Journal of Interactional Research in Communication Disorders*, *12*(2), 234–259. https://doi.org/10.1558/jircd.20401

Kleinke, S., & Bös, B. (2022). Dementia through the lens of family care partners: Carework discourses in German and British public online discussions. In B. Davies & M. Maclagan (Eds.), *Dementia Caregiving East and West: Issues of Communication* (pp. 70–85). Cambridge Scholars.

Leuckert, S., & Leuckert, M. (2020). Towards a digital sociolinguistics: Communities of Practice on Reddit. In S. Rüdiger & D. Dayter (Eds.), *Corpus Approaches to Social Media* (pp. 15–40). John Benjamins Publishing Company. https://doi.org/10.1075/scl.98.01leu

Locher, M. A., & Graham, S. L. (2010). *Interpersonal pragmatics* (1st ed.). De Gruyter Mouton. https://doi.org/10.1515/9783110214338

Locher, M. A., & Thurnherr, F. (2017). Typing yourself healthy: Introduction to the special issue on language and health online. *Linguistik Online*, *87*(8). https://doi.org/10.13092/lo.87.4170

Markham, A., & Buchanan, E. (2017). Research Ethics in Context : Decision-Making in Digital Research. In M. T. Schäfer & K. van Es (Eds.), *The Datafied Society: Studying Culture through Data* (pp. 201-210). Amsterdam University Press. https://doi.org/10.1515/9789048531011-017

Nonaka, I., & Takeuchi, H. (1995). *The Knowledge-Creating Company: How Japanese Companies Create the Dynamics of Innovation.* Oxford University Press. https://doi.org/10.1093/oso/9780195092691.001.0001

Panahi, S., Watson, J. A., & Partridge, H. (2012). Social media and tacit knowledge sharing: Developing a conceptual model. *World Academy of Science, Engineering and Technology*, *6*(4), 648–655. https://publications.waset.org/5672.pdf

Petersen, N., König, H.-H., & Hajek, A. (2020). The link between falls, social isolation and loneliness: A systematic review. *Archives of Gerontology and Geriatrics*, *88*, 104020. https://doi.org/10.1016/j.archger.2020.104020

Pleyer, M. (2025). "I still hope it's just a blip": Constructing life with dementia in a public digital health community. *Discourse, Context & Media, 68*, 100953. https://doi.org/10.1016/j.dcm.2025.100953

Rabeharisoa, V., Moreira, T., & Akrich, M. (2013). Evidence-based activism: Patients' organisations, users' and activist's groups in knowledge society. *CSI Working Papers Series*, *33*, 1–25. https://minesparis-psl.hal.science/hal-00822864v1/document

Rudolf Von Rohr, M.-T., Thurnherr, F., & Locher, M. A. (2019). Linguistic Expert Creation in Online Health Practices. In P. Bou-Franch & P. Garcés-Conejos Blitvich (Eds.), *Analyzing Digital Discourse New Insights and Future Directions* (pp. 219–250). Palgrave Macmillan. https://doi.org/10.1007/978-3-319-92663-6_8

Ryle, G. (2009). *The Concept of Mind: 60th Anniversary Edition* (1st ed.). Routledge. https://doi.org/10.4324/9780203875858

Schneider, C. (2025). Deictic and non-deictic reference at the online-offline nexus: Discussing death on Reddit. Discourse, *Context & Media*, 66, 100899. https://doi.org/10.1016/j.dcm.2025.100899

Schneider, C., & Bös, B. (2019). *'We are not doctors'—Identity work among caregivers in a virtual Community of Practice on Facebook* [Poster Presentation]. Inaugural LabFest. https://doi.org/10.13140/RG.2.2.26129.81764

Schneider, C., & Bös, B. (2024, 24 April). "I'm an RN and looked up the medications" – A corpus pragmatic approach to negotiating lay and professional expertise in a digital dementia support group [Paper Presentation]. *Expert and Lay Voices in Health Communication*, Jagiellonian University, Online.

Sillence, E. (2017). Having faith in the online voice. Exploring contemporary issues of trust, language and advice in the context of e-health. *Linguistik Online*, *87*(8). https://doi.org/10.13092/lo.87.4175

Tagg, C., & T. Spilioti (2022). Research ethics. In C. Vásquez (Ed.), *Research Methods for Digital Discourse Analysis* (pp. 91-113). Bloomsbury.

Tee, M. Y., & Karney, D. (2010). Sharing and cultivating tacit knowledge in an online learning environment. *International Journal of Computer-Supported Collaborative Learning*, *5*(4), 385–413. https://doi.org/10.1007/s11412-010-9095-3

Vydiswaran, V. G. V., & Reddy, M. (2019). Identifying peer experts in online health forums. *BMC Medical Informatics and Decision Making*, *19*(Suppl 3), 68. https://doi.org/10.1186/s12911-019-0782-3