

Open online peer support on dementia for family care partners in the Finland-Swedish minority context[☆]

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ABSTRACT

The aim of this study is twofold. On the one hand, it investigates what possibilities there are to find open online support discussions for Finland-Swedish family care partners of people living with dementia. On the other hand, it analyzes how support is expressed in those open discussions that can be found. The data of the study consist of two subsets: web pages and social media accounts of dementia care providers and Swedish-language media in Finland especially, and nine open Facebook threads with discussions on dementia expressing support to family care partners of people living with dementia. The first dataset is analyzed utilizing a passive netnographic method. Focusing on expressions of emphatic communication, the second dataset is analyzed using content analysis and coded with the mixed methods software MAXQDA. As the results show, it is difficult to find open online channels for support discussions on dementia in Swedish in Finland. At the same time, the discussions that can be found convey how important they are to those participating in them. The availability of open online support discussions provides additional comfort and help to those living with dementia and their care partners. Online support discussions are thus important per se, irrespective of the fact that offline services are provided fully and sufficiently also in Swedish in Finland.

1. Introduction

This paper explores the possibilities for family care partners of people living with dementia to engage in open online support discussions in the Finland-Swedish minority context, which has not been investigated before. Although Swedish is a national language in Finland with a strong legal position (Liebkind et al., 2007), the much smaller proportion of first language speakers (5.1 %) compared to the other national language, Finnish (84.9 %),¹ makes Swedish less visible in public spaces, including online settings (Lindell, 2021). Nonetheless, being able to find support also in Swedish when you live in Finland is important, not the least when facing health-related challenges in your life (cf. Mustajoki 2020; Nyqvist et al., 2021).

As discussed by Romero Mas (2021), having support of their peers is crucial for family care partners of persons living with dementia. Peer support also has a positive impact on the quality of life for family care partners since sharing experiences with others facing similar problems increases your well-being (Zloty et al., 2011). Support groups have traditionally been provided offline, but as Romero Mas (2021: 11) points

out “[t]he Internet could contribute much more to supporting the needs of caregivers as it offers the possibility of uniting people and providing them with the tools to share their knowledge”. The purpose of this paper relates to the latter perspective, that is, how the internet contributes to providing low threshold peer support to Swedish-speaking family care partners in Finland.² The focus is exclusively on open online peer discussions, which play an important role in providing online support that may otherwise be difficult to find due to demographic factors (age, minority context).

The paper thus explores bottom-up family care partner open discussions in online settings, which is one of the aspects highlighted in this article collection on dementia in social media discourse and digital interaction. On the one hand, the aim of the paper is to find out what possibilities there are to find and participate in open discussions online in Swedish in Finland. On the other hand, the purpose is to analyze the characteristics of those open discussions in Finland-Swedish settings that are available. How is empathy to care partners of people living with dementia expressed in this specific mediated context compared to other similar mediated micro-contexts? The focus will be on nine open

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¹ Statistics Finland, 2024.

² On the importance of low-threshold resources especially in dementia contexts, where care partner mobility is often restricted, see Kleinke (2022).

discussions on Facebook that can be found and read in web browsers without logging into the platform itself. All nine discussions represent emphatic mediated communication of a similar type as the Facebook support group discussions on diabetes analyzed by Pounds et al. (2018). Comparisons to Pounds et al. (2018), who offer a methodological template to be explored in interactions in various online groups, will therefore play an important role in this paper.

Section 2 provides background information on the Swedish-speaking minority in Finland and how welfare services and support to people with dementia are organized in Finland. Section 3 presents earlier studies on emphatic communication in online settings to contextualize section 6.2, followed by the data and methodology of the study (sections 4–5). After that I move on to presenting the findings, starting with the possibilities to find online support discussions in Swedish in Finland in section 6.1 and continuing with an analysis of the nine open discussions on Facebook in section 6.2. The paper ends with conclusions in section 7.

2. The Swedish-speaking minority and the health care system in Finland

At the end of 2023, 286,030 of the 5.6 million inhabitants of Finland were registered as Swedish-speaking, 4.8 million as Finnish-speaking, 2,051 as Sami-speaking and 0.6 million as speakers of other languages (Statistics Finland, 2024). Despite being a numerical minority of only 5.1 % of the population in Finland, Swedish has a legally strong position as a national language. This can be explained by Finland's common past with Sweden (Liebkind et al., 2007; Suksi, 2023). Finland was part of the Swedish kingdom for 600 years until 1809 and during the Russian period in 1809–1917, Swedish remained the main language of public administration, until Finnish slowly gained ground and started dominating in the decades before Finland became independent in 1917 (Saari, 2012; Halonen et al., 2015). In the Finnish constitution from 1919 renewed in 1999, Finnish and Swedish were given equal rights as official national languages of the new republic (Liebkind et al., 2007; McRae, 2007; Saari, 2012). This is still the case today, which means that all public service, including health care and health information, is provided by law both in Finnish and Swedish (see below). However, due to the differences in size of the two language groups, Finnish is more visible in public spaces, especially on the national level but also in bilingual cities with Finnish as the majority language (Latomaa and Nuolijärvi, 2005; Lindell, 2021).

The Language Act in the Constitution of Finland (1922, renewed in 2023),³ guarantees Finnish citizens the right to use either Finnish or Swedish in courts of law and in communication with other national authorities, including public health care services. In contrast to other officially bilingual/multilingual countries, such as Switzerland, Belgium and Canada, there are no territorially secured language environments in Finland, except for the self-governing and unilingually Swedish province of the Åland Islands with its 27,500 inhabitants. Rather, municipalities, not regions, are legally defined as unilingual in Finnish or Swedish or as bilingual with either Finnish or Swedish as the majority language, depending on the percentage or number of speakers of the two languages in the municipality.⁴ Bilingual municipalities are required to provide services both in Finnish and Swedish (Latomaa and Nuolijärvi, 2005; Suksi, 2023).

The Swedish-speaking population lives primarily in provinces along the southern and western coast of Finland (Latomaa and Nuolijärvi, 2005). In these provinces (except for the Åland Islands that are unilingually Swedish by law) all public health care services (and other public services), including dementia care, should be provided in the same way in both languages, that is, in Finnish and Swedish (cf. above).

Studying the other national language is compulsory in school and higher-level education both for Swedish- and Finnish-speaking Finns in the whole country, apart from the Åland Islands (Latomaa and Nuolijärvi, 2005). The level of proficiency in the other language varies within both language groups, but Swedish-speaking Finns are more often expected to be able to switch to Finnish than the other way around. However, while some Swedish-speaking Finns are highly bilingual, others may use Finnish seldom in their daily life, for example, in municipalities on the western coast of Finland (Ostrobothnia) where Swedish is spoken by a vast majority of the population (cf. Stenberg-Sirén, 2021). Therefore, while health services are by law, *de jure*, available in both languages, it is especially relevant to ensure that also the Swedish-speaking Finns receive this care *de facto* in their first language, something which Finnish-speaking Finns can usually take for granted (cf. Suksi, 2023).

Services for people with memory disorders are provided and administered by the 21 self-governing wellbeing service counties in Finland (fi. *hyvinvointialue*, Sw. *välfrädsområde*), and in the case of the capital Helsinki, by the municipality. The new system of wellbeing service counties taking care of health care, social welfare as well as rescue services instead of municipalities was launched as late as in 2023 (Ministry of Social Affairs and Health, 2024). The city of Helsinki and seven of the wellbeing service counties are bilingual, which means that all services should be provided in both Finnish and Swedish (Lindholm et al., 2021).⁵ However, for some municipalities on the southern coast of Finland, where the majority of the population is Swedish-speaking (such as Raseborg and Pargas), becoming part of a large wellbeing service county with Finnish as the dominating language has weakened the formerly strong administrative role of Swedish, which could potentially have an impact also on the quality of services provided in Swedish in the future (cf. Julkunen et al., 2023).

In addition to services provided by health care professionals and memory nurses working within wellbeing service counties, counselling and guidance of people with dementia and their families is also provided by organizations such as the Alzheimer Society of Finland (Löf, 2022). This non-profit organization, which is a national umbrella organization with 14,500 members, campaigns “for the rights of people with dementia and their caregivers” to “raise awareness of dementia, disseminate information and offer advice” (The Alzheimer Society of Finland, 2024a). It was established in 1988 and has 41 local associations across Finland that “offer information, activities and peer support to people with dementia and their loved ones” (Alzheimer Society of Finland, 2024a). 18 of these local associations run so-called *Memory pilot centres* (Fi. *Muistiluotsi*, Sw. *Minneslots*). These local expert and support centers form an interconnected national network of services for people with dementia and their families (Alzheimer Society, 2024b – for a more detailed presentation of the Alzheimer Society and the services it provides, see section 6.1 below).

3. Emphatic communication in online settings

As discussed in the introduction, the Facebook discussions on dementia analyzed in this article (section 6.2) represent emphatic communication in open online settings. The discussions thus also represent the kind of peer support to family care partners of people living with dementia that the internet, according to Romero-Mas (2021), could provide more of. As pointed out by Pounds et al. (2018: 35), who analyze expressions used in a diabetes support group on Facebook, empathic concern is greater among those with similar life experiences

⁵ For a map of the service counties, see <https://stm.fi/en/wellbeing-service-counties-on-the-map1>. The bilingual counties are Central Ostrobothnia, Ostrobothnia, Southwest Finland, West Uusimaa, Vantaa and Kerava, East Uusimaa, Kymenlaakso. The share of Swedish-speaking inhabitants varies between 1 and 50% (Lindholm et al. 2021: 6).

³ See https://finlex.fi/en/legislation/2003/423#chp_1_heading.

⁴ If the Swedish/Finnish minority in a municipality comprises at least 8% or 3,000 of the inhabitants, the municipality is bilingual by law.

and “interaction in online support groups provides the ideal conditions for both expression and perception of empathy”. Pounds et al. (2018: 35) refer to Morrow (2006), who stresses the fact that support group members’ mutual expressions of positive regard has an important solidarity-building function that may take the shape of, for example, encouragement, reassurance, praise, expressions of affect and sympathy, unconditional support or rejections of expressed or non-expressed negative self-evaluation or, such as *I’m sorry to hear and good luck*.

The units analyzed by Pounds et al. (2018) are *emphatic communicative acts*, which consist of different types of expressions performing empathic communicative acts (ECAs) in online interactions. Pounds et al. divide these ECAs into several categories, such as *Core empathy-seeking acts*, *Core empathy giving acts* and *Peripheral empathy giving acts*, all of which also cover several more specific acts, such as ‘Acknowledging feelings’, ‘Sharing similar feelings/experiences’, ‘Expressing sympathy’ and ‘Expressing thanks’. As they conclude, their study offers “a flexible methodological template and coding options that may be applied to explore interactions in other online groups, whether Facebook-based or not” (ibid: 43). The purpose of this paper is to utilize this template to analyze the nine Facebook support discussions on dementia in Swedish in Finland.

4. Data

The aim of this study is twofold: to investigate where it is possible to find open online support discussions on dementia in Swedish in Finland, and to analyze how support expressed in those discussions that can be found by utilizing the methodological template offered by Pounds et al. (2018). The data of this study therefore consist of two subsets, the second of which is a result of the first one:

1. Web pages and social media accounts both generally and more specifically of wellbeing service counties, organizations providing support on dementia and Swedish-language media in Finland.
2. Nine open Facebook threads with discussions on dementia expressing support to family care partners of people living with dementia.

Finding online support discussions on dementia in Swedish in Finland was challenging. Some discussions could, nonetheless, be found primarily on Facebook, which (in Finland, together with WhatsApp) is the social media platform favored by the age-groups that family caretakers of people with dementia typically represent (cf. Saarenmaa and Kohvakka, 2019). In step two of the study, I therefore decided to focus on nine open Facebook threads that I had found. The fact that it was Facebook where I could find some open discussions in Swedish in Finland is expected considering the nature of Facebook as a social networking site (Boyd and Ellison, 2008). Facebook is a dynamic and participatory platform, and the generic context of Facebook has been found to promote a good sense of social connection among participants (Page, 2012: 73; Georgalou, 2015: 31). Like other computer-mediated contexts, Facebook seems to enhance the possibilities to express affect of various kinds (Page, 2012: 73; Eisenlauer 2017). The perception that the asynchronous communication on Facebook is less face-threatening than face-to-face conversation in a similar way as, for example, letters (Biber and Finegan, 1989) has also been attested in questionnaire data collected from updaters (Page, 2012: 73). Georgalou (2015: 31, referring to Androutsopoulos, 2010: 210) points out that comments on Facebook “constitute indicators of engagement with a post as well as a way to provide background information and engage in identity debates triggered by the given post”.

The nine Facebook threads chosen, listed in Table 1, all focus on how to deal with dementia as a family care partner. Furthermore, they all include at least some comments showing support to those either writing the status updates on dementia themselves or being interviewed in articles shared. In the analysis I will focus on these comments. I extracted them with the help of [Export.Comments.com](https://www.exportcomments.com), which included all nested

Table 1

The Facebook threads on dementia analyzed.

| | Facebook profile | Year published | Facebook status update | Number of comments |
|---|--|----------------|---|--------------------|
| 1 | Public service media | 2022 | Article about a woman whose husband has Alzheimer’s and a man whose parents have Alzheimer’s | 4 |
| 2 | Newspaper | 2019 | Article about a woman whose husband has Alzheimer’s | 13 |
| 3 | Newspaper | 2019 | Article about a man whose wife has Alzheimer’s | 7 |
| 4 | Newspaper | 2022 | Article about a woman whose parents have Alzheimer’s | 3 |
| 5 | Female person with family members who have had Alzheimer’s | 2019 | Article about medication to people with Alzheimer’s and the importance of belonging to a family | 18 |
| 6 | Female politician | 2021 | Update about the updater’s mother, who has Alzheimer’s, on Mother’s Day | 82 |
| 7 | Female politician | 2021 | Reposting of an update about the updater’s mother, who has Alzheimer’s, on Mother’s Day | 15 |
| 8 | Male composer and musician | 2022 | Poem about the updater’s mother, who has Alzheimer’s | 21 |
| 9 | Female person | 2014 | Update about the updater’s aunt, who has Alzheimer’s and should move into a nursing home | 32 |
| | | | | 195 |

comments but left out comments with visibility restrictions set by the commentators themselves. Hence, all the data analyzed in this paper consist of discussions that are open and publicly available. As pointed out in the introduction, all discussions included can also be found by utilizing the search function in web browsers without being logged into Facebook. To avoid unnecessary exposure of participants, all names have been changed in the comments shown, and no comments with private information are shown. In addition, contextual information about the updates and updaters is provided in a general enough form without directly referring to the specific settings where they can be found. I thus follow similar principles in using publicly available Facebook data as, for example, Pérez-Sabater (2012).

As shown in Table 1, the Facebook data set consists of nine status updates open to everyone published primarily between 2019 and 2022. To increase the size of the data, one older thread from 2014 with a similar topic and several comments was included.⁶ Four of the Facebook updates were published on the accounts of newspapers or public service media with links to articles on web pages (updates 1–4, Table 1). All these articles were about family care partners of persons living with dementia. The five other updates were made by individuals. One of them posted an article about the importance of family for persons with dementia living in a nursing home and commented on this herself as well (update 5). The remaining four updates did not include any links to articles. Two updates were written by a well-known female politician on Mother’s Day, and the latter of these (update 7) was a reposting of the

⁶ No other similar older threads from 2014 to 2019 were found during the searches conducted.

former that included a long text about her mother who has Alzheimer's (update 6). In update 8, a male composer and musician posted a picture of his parents and wrote a poem in the update to his mother, who has Alzheimer's. Finally, the last update in the data by a female person was about the difficult choice to be made when a family member needs to move into a nursing home (update 9).

5. Methodology

The first dataset, analyzed in section 6.2, was investigated in a highly explorative way since no information on online support discussions on dementia in Swedish in Finland has been collected and reported on before. A passive netnographic method was used, that is, I only observed data available online (cf. Costello et al., 2017). I first made general searches on the web and social media platforms (Facebook, Instagram, Twitter/X, YouTube) utilizing the typically Finland-Swedish expressions *minnessjuk* 'memory sick' and *minnessjukdom* 'memory sickness', which are not used in Sweden, and then continued with the standard Swedish expressions *demens* 'dementia', *dement* 'person with dementia' and *Alzheimer(s)* that are used in both Sweden and Finland.⁷ The first pilot searches were made in 2020 and early 2022, followed by more systematic searches in the fall and summer of 2022. Already during the first searches it became clear that it was difficult to find any support groups focusing on dementia in Swedish in Finland.⁸ Based on the results from these first searches I narrowed down the online sites investigated in December 2022 to those where the likelihood to find open support discussions on dementia – or links to such discussions – was the highest: the websites and social media accounts (Facebook, Instagram, YouTube) of municipalities/wellbeing service counties, the Alzheimer Association of Finland, and Swedish-language media in Finland. These settings were then explored in detail and followed up during four different periods: February 2023, June 2023, November 2023, and March 2024. By repeating the searches several times, I wanted to secure that I did not miss any new discussions that could have been added to the second dataset.

In the analysis in section 6.2, the focus will be on the comments to the nine Facebook status updates, which are 195 in total and range between 3 and 82 per update (Table 1). The comments are quite similar despite the different character of the updates (linking of articles, poems written to a parent etc.). They were analyzed by using qualitative content analysis (Graneheim et al., 2017) and coded in the mixed methods software MAXQDA (which was also used for storing samples of web pages and social media updates in study 1). I first coded the contents of the comments inductively and then combined and refined the codes before finalizing the thematic coding of the whole dataset. The analytic approach is thus similar as in, for example, Pounds et al. (2018).

6. Results and discussion

6.1. Searching for online peer support

The purpose of the first part of the study was twofold: firstly, to investigate how easy/difficult it is to find online support channels directed to family care partners of people living with dementia and secondly, to find data from open support groups to analyze in the second part of the study. The focus in this section will be on what resources can be found on or through the online sites and social media accounts

⁷ The Finland-Swedish expressions containing *minnessjuk* 'memory sick' have a counterpart in Finnish (*muistisairas* 'memory sick'). They are widely used in Finland, but cannot, for example, be found in the Swedish Academy dictionaries available at svenska.se.

⁸ A couple of closed Facebook groups could be found. In addition to being ethically problematic to collect data from for a study on authentic interaction, they displayed little activity and few participants.

(Facebook, Instagram, YouTube) of the main dementia care providers in Finland. After first discussing the online channels of the public health care system providers, I move on to showing what online resources are provided by the Alzheimer Society and the local Alzheimer organizations that work closely with public health care providers. Even though my main aim is to find open online support discussions in Swedish and/or links to them, the presentation will also include some general information on the amount of information provided in Swedish in the online settings investigated. The section ends with a discussion of how the Facebook profiles of Swedish language media providers in Finland turned out to be the online setting where open support discussions could finally be found.

The web searches revealed great variation in the structure and contents of the web sites of the seven bilingual wellbeing service counties established in 2023 and the city of Helsinki (which forms a unit of its own, see section 2). By March 2024, most of them presented information on dementia adequately in both Finnish and Swedish on their web pages. Except for one county (Central Ostrobothnia with a small minority of Swedish speakers), which included a link to an Instagram account in Finnish on the web page "Services to elderly", none of the wellbeing service counties neither the city of Helsinki mentioned any online support groups, social media accounts or alike on their webpages. Instead, the focus was almost exclusively on providing information on offline services and telephone counselling. Accounts of nursing homes administered by the wellbeing service counties (and the city of Helsinki) could, however, be found through searches directly on social media platforms, such as Facebook and Instagram. Figs. 1 and 2 show two typical examples from nursing homes in bilingual areas where Swedish is spoken by a majority. In Fig. 1 from Southwestern Finland the update is written in Swedish and Finnish and in Fig. 2 from Western Finland the update is written only in Swedish. Both updates show pictures of activities at the nursing homes accompanied by positively framed texts about Easter and Valentine's Day, respectively. The positive framing is further underlined by emojis. While there are no comments to the Instagram post (Fig. 2), there are two short comments to the Facebook post (Fig. 1), one that consists only of emojis and one that expresses the evaluation *Så fint* 'so nice'. Neither the websites nor the social media accounts of wellbeing counties or units administered by them, thus displayed the type of open



Fig. 1. Facebook update about Easter by a nursing home; text in Swedish and Finnish ("Today also Eastern crafts").



Fig. 2. Instagram post by a nursing home; text in Swedish about Valentine's Day. ('To honor Valentine's Day, we have a visit by the school. And a good dessert. Happy Valentine's Day to you all').

online discussion that I was looking for.

Most of the web sites of the wellbeing service counties and the city of Helsinki have links from their websites on dementia either to the Alzheimer Society of Finland or the Memory pilot centres run by member organizations of the society. The Alzheimer Society is a bilingual organization, and the web pages of the society offer extensive information also in Swedish (<https://www.muistiliitto.fi/sv/framsidan>), but less or less updated information than in Finnish. Some pages directed to speakers of Swedish contain only or mainly information in Finnish, and most online activities are offered in Finnish only. For example, the society is active on social media (Facebook, X, Instagram) and runs a blog, but posts nothing in Swedish on these platforms. On the local level, the amount of information and activities in Swedish varies greatly. Some local Alzheimer's Associations in bilingual areas with a Finnish majority, such as the capital Helsinki, offer minimal information and activities in Swedish. Fig. 3 shows (part of) the front page of the website in Finnish in Helsinki and (part of) the only page available in Swedish, which presents the association very briefly in Swedish even though Helsinki is an officially bilingual city with some 37,000 Swedish-speaking inhabitants. The only information provided in Swedish can thus be found on one single page on the website that is otherwise completely in Finnish.

Other local Alzheimer's Associations in bilingual areas have more balanced webpages in both languages and provide much more information and activities in Swedish. Fig. 4 shows the Swedish page of the local Alzheimer's Association in Southwestern Finland, where the web pages have the same structure in Finnish and Swedish. While only the organization's Facebook group in Finnish is embedded into the front page of the website in Finnish, both the Facebook group in Finnish and Swedish have been embedded into the frontpage in Swedish. The YouTube channel linked to on both pages is bilingual and contains also recently published videos in Swedish. However, a closer look at the Facebook groups, YouTube channels and Instagram accounts administered by the bilingual Alzheimer's organizations with postings in Swedish revealed that there are hardly any comments to the postings and videos, only likes or a few comments of the type shown in Fig. 1 above. To be able to analyze longer stretches of support discourse in online settings, I therefore turned to the websites and social media

accounts of Swedish-language media in Finland. No discussions or comments to articles on dementia could be found on the websites (the commentary field was typically closed). However, some articles had been shared on Facebook and received a fairly good number of comments there. This encouraged me to look also for other updates on dementia on Facebook, actually the only platform containing relevant data, which resulted in a small collection of Facebook threads where support is shown and expressed to care partners of persons living with dementia.

6.2. Comments to Facebook status updates on dementia

In my analysis of the characteristics of those open support discussions on Facebook that I have been able to collect, I will focus on what type of support is expressed in users' comments and how it is presented. I start by describing the nature of interaction in the threads more generally (examples 1–4) before moving on to presenting the results of my qualitative content analysis in Table 2, each exemplified and discussed in examples (5)–(20).

As pointed out, all comments to the updates in the nine Facebook threads primarily express empathy (cf. Pounds et al. 2018). Many of them also express comfort and gratitude to the updaters or the persons presented in the updates for bringing forth issues important to everyone experiencing dementia in their family. Most of the comments are either directed to the person who has written the update – see examples (1) and (2).

(1) **Tack för dina tankar!** Jag delar dina känslor. ❤️

'Thank you for your thoughts! I share your feelings.'
(Fb_update_6#8)

(2) Verkligt innerligt vacker dikt, John 📖

'Really sincerely beautiful Poem, John' (Fb8#2)

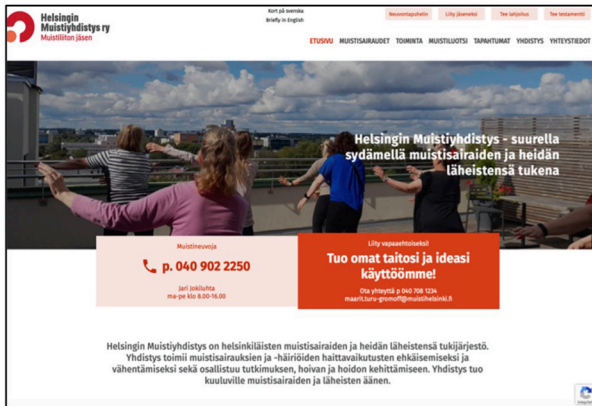
In a few cases the commentator explicitly refers to something written by another commentator in the same thread. These cases highlight the interactive character of the threads stressing the need for exchange and mutual encouragement among family care partners. They also show the potential of digital interactions for off-line personal coping strategies of family care partners, as in example (3) from Fb9, dealing with how difficult it is to make the decision to move a family member into a nursery home. The commentator first expresses empathy by saying that she understands that it feels difficult for the updater. After that she refers to another commentator by writing *men som Anna skriver* 'but as Anna writes' and then goes on to express her support to the updater, encouraging her by pointing out that she is a wise woman with a good heart who will make a good decision for the person living with dementia.

(3) **Förstår att det känns svårt** – men som Anna skriver – du är en klok kvinna med gott hjärta! Jag vet att du tar beslutet med hennes bästa i tanken!

'I understand that it feels difficult – but as Anna writes – you are wise woman with a good heart. I know that you are making the decision with her best interest in mind!' (Fb9#13)

In addition to cases where commentators recontextualize something said by another commentator in their own comment to the update or the updater as exemplified in (3), there are also a few cases where the commentators directly respond to one another's comments. Example (4) shows such a response from Fb5 (on the importance of family for people living with dementia). In the first comment, the third commentator in the thread writes that the sense of belonging is the most important thing also for those living with dementia. The sixteenth commentator in the thread responds directly to this by concluding that this is so true but that you often do not understand it before you start missing it (i.e., the sense of belonging).

Frontpage in Finnish



'Briefly in Swedish'

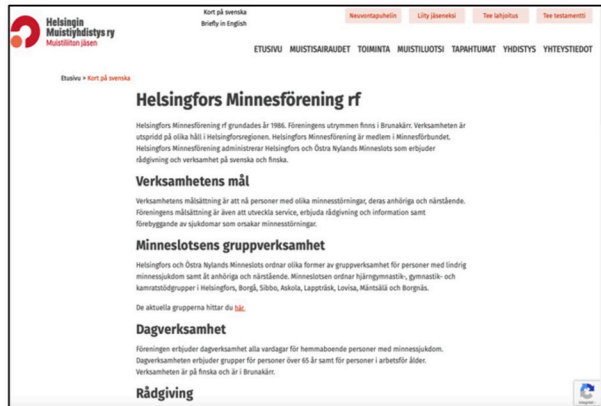
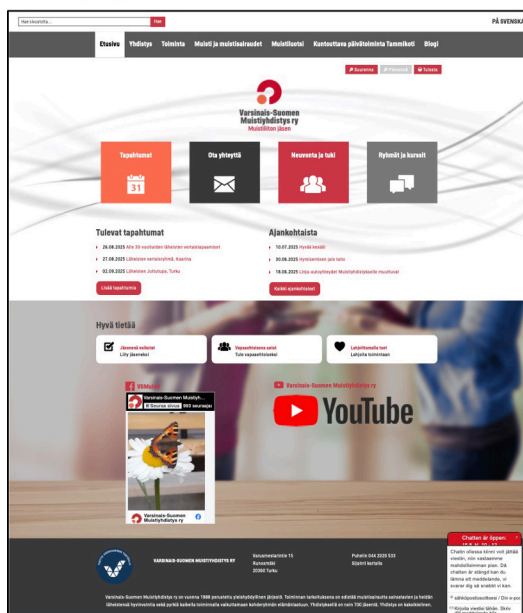


Fig. 3. The webpages of the Alzheimer's Association of Helsinki in Finnish and Swedish, respectively. (<https://muistihelsinki.fi>; <https://muistihelsinki.fi/kort-pa-svenska/>).

Front page of web site in Finnish



Front page of web site in Swedish

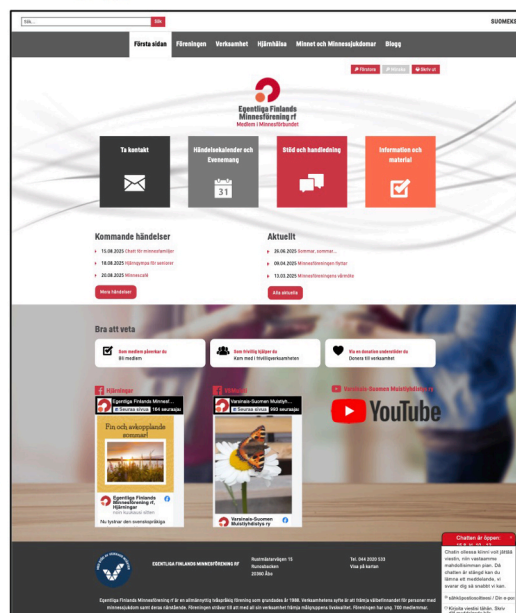


Fig. 4. The webpages of the Alzheimer's Association of Southwest Finland in Finnish and Swedish, respectively (<https://www.muistiturku.fi/fi/>; <https://www.muistiturku.fi/sv/>).

Table 2

The results of the content analysis of the Facebook comments.

| Categories coded | Number of codings |
|--|-------------------|
| Non-verbal: emojis and hugs | |
| [1] Heart emojis | 85 |
| [2] Other emojis | 16 |
| [3] Hugs | 12 |
| Verbal: | |
| [4] Beautifully/well written | 72 |
| [5] Thank you | 26 |
| [6] Sharing own experience | 25 |
| [7] I recognize myself in what you write | 24 |
| [8] Touching | 23 |
| [9] Empathy, I understand | 19 |
| [10] Dementia | 17 |
| [11] Support for decision | 15 |
| [12] Your words comforted me | 4 |
| Total: | 338 |

(4) **Det viktigaste är tillhörigheten**, att få vara en social människa bland andra också om man är dement.

'The most important thing is belonging, to be able to be a social human being among others even though you have dementia.' (Fb5#3).

Response:

Det är så sant, det förstår man ofta först när man saknar den. **'This is so true**, you often do not understand this before you miss it.' (Fb5#16)

In the thematic content analysis beyond the general characteristics of the interaction discussed so far, which was conducted using the mixed-method software MAXQDA, most of the comments were assigned several codes, often including verbal and non-verbal means.⁹ Emojis were coded

⁹ To enhance transparency, the (verbal) parts of examples relevant for category assignment are given in bold face.

separately, and hearts were kept separate from other emojis (which consisted primarily of flowers due to two status updates on Mothers' Day). Table 2 presents an overview of the results, which will be discussed and exemplified in the remainder of the section.

As the codes and number of codings in Table 2 show, the supporting function of the Facebook discussions stood out as important to participants and is signaled by both verbal and non-verbal means. The most typical reactions supporting other users in the comments were categories [1], heart emojis (examples (5)–(6); 85 cases in total), and [4], appraisals of how beautifully or well the status update or linked article described people facing dementia in their lives (examples (6 – 8), 72 cases in total). Example (7) additionally illustrates category [2], 'Other emojis' (16 cases) and example (8) category [3], 'Hugs' (12 cases). As the examples show, commentators both use emojis alone to express emotional support, as in example (5), and to emphasize support expressed also verbally, as in examples (6)–(8) (Dresner and Herring, 2010).

(5) ❤️❤️❤️❤️ (Fb6#79).

(6) En så vackert skriven artikel! ❤️.

'What a beautifully written article!' (Fb3#4)

(7) Mycket bra artikel om ett viktigt ämne! ☆.

'A very good article about an important topic' (Fb4#3)

(8) Kram vännen! <3.

'Hugs my friend' (Fb9#27)

The reactions in category [9], 'Empathy, I understand' (19 cases) could be compared to the core empathy giving act 'Acknowledging feelings' discussed by Pounds et al. (2018) in their study of expressions of empathy in a support group on diabetes. In example (9), in the context of having to make the difficult decision to move a family member into a caring home, the commentator first writes that she understands the updater's feeling (that it is difficult to take the decision), and then continues by explicating that it is a big decision to move away from a home that is dear to you.

(9) Kan förstå din känsla. Att flytta från ett kärt hem, antagligen för gott, är ett stort beslut. [...].

'Can understand your feelings. To move away from a beloved home, probably for good, is a big decision.' (Fb9#7)

The Facebook comments show how the status updates on dementia are important also for the commentators themselves. In example (10), coded for category [5], 'Thank you' (26 cases in total), the commentator explicitly thanks the person who has participated in the article on dementia that the newspaper is sharing in the update. In example (11), which also shows one of four cases in the category [12], 'Your words comforted me', the commentator is thanking a well-known politician for her wise and comforting words about her mother who has Alzheimer's. In three cases the updaters or interviewees in the linked articles also explicitly thank the commentators for their support, such as in example (12). Examples expressing thanks are directly comparable to those cases of *peripheral empathy giving acts* that Pounds et al. (2018) categorize as 'Expressing thanks'.

(10) Tack för att du ställde upp.

'Thank you for participating [in the interview].' (Fb2#4)

(11) Tack för din fina text, tröstande ord och livsvisdom ❤️.

'Thank you for your beautiful text, comforting words and life wisdom' (Fb6#24)

(12) Tack för alla uppmuntrande stödjande som ni säger. De tur att jag har så fina vänner. Jag är rörd över att ni bryr er. Kram.

'Thank you for all your encouraging [words] that you say. I am lucky to have such wonderful friends. I am moved by your concern. Hugs' (Fb9#23)

Many commentators in the data use the word *rörande* 'touching' to express that they were moved by the status updates or shared articles, coded as a category of its own ([8], 'Touching'; 23 cases) – see example (13) where the commentator spells out that the text, that is, the article from a newspaper shared in the update, is a reality for many. As illustrated in example (14), several commentators in the data also express explicitly that they recognize themselves in the stories being told in the update and/or the shared article on family members of persons living with dementia (category [7], 24 cases).

(13) En berörande text som är verklighet för många.

'A touching text which is the reality for many.' (Fb2#5)

(14) Vet vad du talar om, krafter 🤔👂.

'I know what you talk about, strength [to you]' (Fb8#12)

Furthermore, there are 25 cases of category [6], ('Sharing own experiences') where the commentators write about their own experiences of family members living with dementia as illustrated in examples (15 – 16). These cases, as well as example (14) from category [7] correlate with the category 'Sharing similar feelings/experiences' in the study by Pounds et al. (2018).

(15) Inte lätt beslut. Men det du ordnar blir nog så bra för henne. Jag är nämligen i samma sits för min mamma. Jag vet inte heller hur jag skall göra.

'Not an easy decision. But what you are organizing will be so good for her. I am in the same situation with my mother. I do not know what to do either.' (Fb9#16)

(16) Min farmor hade sjukdomen och även min pappa. Jag vände sorgen över detta genom att samla ihop anhöriger berättelser från Sverige, Norge och Finland i en bok om anhörigskap och Alzheimers.

'My grandmother had the disease and my dad also. I turned my sorrow over this into collecting stories by relatives from Sweden, Norway and Finland into a book about being a relative and [facing] Alzheimer's. (Fb1#1)

In example (17), the commentator expresses her support to the updater who has written about the difficult decision to be made when a family member needs to be moved into a nursing home, representing category [11], 'Support for decision' (15 cases in total). Even though the category 'Encouraging/reassuring/supportive considerations' in Pounds et al. (2018) is broader, the cases coded in this group show a strong resemblance with many of their cases.

(17) Du gör rätt beslut. Det är bättre att flytta i tid att man hinner bekanta sej med sitt nya boende. ♥️.

'You are making the right decision. It is better to move in time so that one has time to get acquainted with one's new home.' (Fb9#21)

Finally, there are also 17 reactions that I have simply coded with 'Dementia'. In these cases, the commentators are focusing on the nature of the disease and mostly write about things that make the life of persons living with dementia easier, as in examples (18) and (19), illustrating what Kleinke (2022: 240) describes as "[a]lternative 'Carpe diem' discourses", which "relate to an attitude of 'making the best of it'" and "focus on appreciating the positive aspects of life". There are, however, also three comments that underline the shared experience of the cruel nature of the disease – see example (20), which could be related to what Kleinke (2022: 240) calls discourses of 'Death, degeneration, and decline'.

(18) Dementa brukar känna sig tryggt i en hemmiljö. De brukar minnas barndomen och ungdomstiden mycket bra!!

'People with dementia usually feel safe in a home environment. They tend to remember their childhood and youth very well!!!' (Fb9#6)

(19) Jag undrar om inte det allra viktigaste är TRYGGHET, men det hör kanske ihop med tillhörighet.

'I wonder if the most important thing is not SECURITY, but that is perhaps related to belonging.' (Fb5#4)

(20) Ingen värre sjukdom finns, hemskt i början för den drabbade och hela förloppet är förfärligt för de närmaste.

'There is no worse disease, terrible first for the person affected and the whole course of the disease is horrible for close relatives.' (Fb1#2)

To summarize, analogously to Pounds et al (2018), the analysis of the comments in those few open online discussions on dementia that you can find in Swedish in Finland characterizes these care partners' interactions as highly emphatic and shows that there is clearly a need for this type of peer support. Not only do the discussions seem to play an important role for those who are posting an update on dementia on Facebook and those who have been interviewed in articles shared on Facebook. The discussions also revealed an important empowering function for those participating in the discussions as commentators which rests in both, their interactivity as well as mutual support and solidarity – both potentially enhancing their shared experience of a 'digital community'. This intertwines care partners' daily off-line practices with a sense of mutual support and solidarity instantiated in their on-line interactions with users involved in similar situations.

7. Conclusions

The purpose of this study has been twofold. On the one hand, I wanted to investigate what possibilities there are to find open online support discussions for family care partners of people living with dementia when you belong to a linguistic minority such as the Swedish-speaking Finns. On the other hand, I wanted to explore how support is expressed in discussions that can be found. As shown, it turned out to be challenging to find any online support discussions at all. While offline dementia services are organized well in both national languages in Finland, Finnish and Swedish, and information about this is generally provided in a good manner on websites, the possibilities for Swedish-speaking family care partners in Finland to find and participate interactively in open online support discussions on dementia within their own linguistic and cultural setting, are limited. At the same time, the nine threads on publicly open Facebook accounts that I found and analyzed in part 2 of the study indicate the great potential of open online spaces as a special form of mediated discourse in Swedish in Finland where you can discuss dementia from the perspective of family care partners. The atmosphere in the nine open Facebook threads analyzed was overwhelmingly positive leading to comfort and support for both updaters/interviewees in articles shared in the updates and those commenting on the updates. Providing online spaces for support on dementia also for linguistic minorities is therefore an important task to work on. To return to what Romero Mas (2021: 11) concludes, the internet has a great potential to offer family caregivers of people living with dementia possibilities to unite with others in the same situation and provide them with tools to share experiences and knowledge, which includes a potential for forming Digital Communities of Practice, in which users can discursively frame their daily offline caring experiences. In other words, online support is important also *per se*, not only to compensate offline services that potentially do not work well enough. In the Finland-Swedish setting, it would therefore be important to try to increase the availability of low-threshold online support discourses that provide additional comfort and help to those living with dementia and their care partners.

Declaration of competing interest

The author declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The authors do not have permission to share data.

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