

Self-organizing knowledge management might improve the quality of person-centered dementia care: a qualitative study

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Abstract

Background: In institutional dementia care, person-centered care improves care processes and the quality of life of residents. However, communication gaps impede the implementation of person-centered care in favor of routinized care.

Objective: We evaluated whether self-organizing knowledge management reduces communication gaps and improves the quality of person-centered dementia care.

Method: We implemented a self-organizing knowledge management system. Eight significant others of residents with severe dementia and six professional caregivers used a mobile application for six months. We conducted qualitative interviews and focus groups afterward.

Main findings: Participants reported that the system increased the quality of person-centered care, reduced communication gaps, increased the task satisfaction of caregivers and the wellbeing of significant others.

Conclusions: Based on our findings, we develop the following hypotheses: Self-organizing knowledge management might provide a promising tool to improve the quality of person-centered care. It might reduce communication barriers that impede person-centered care. It might allow transferring content-maintaining tasks from caregivers to significant others. Such distribution of tasks, in turn, might be beneficial for both parties. Furthermore, shared knowledge about situational features might guide person-centered interventions.

Keywords: eHealth, collaborative computing, qualitative study, distributed cognition, institutional care, Alzheimer's disease, humanistic gerontology

1. Introduction

People with dementia have a lower quality of life if they live in care homes, compared to living at home [1]. Residents of care homes have a substantial need for psychosocial support [2]. The standard of delivering this support shifted from standardized health care to person-centered care [3, 4]. Person-centered care prioritizes the quality of life of residents [3, 4]. However, the implementation of person-centered care is stagnant [5]. Communication gaps inhibit person-centered care [6]. We propose to use self-organizing knowledge management to fill these gaps.

1.1. Person-centered care

Person-centered care emphasizes individual needs of residents to maximize self-determination and well-being [7, 4]. Person-centered care improves the care processes and the quality of life of residents [8, 9, 10]. Health-care professionals understand person-centered care as the most desirable approach to provide psychosocial support [11, 2]. Person-centered care realizes commonly accepted humanitarian and ethical values [12]. Despite its broad theoretical acceptance, the implementation of person-centered care is often impeded, in favor of routinized care [1]. Such non-individualized processes impede relationships between residents and caregivers [13, 14].

1.2. Hurdles of person-centered care

Profit maximization in care institutions reduces administrative support for person-centered care

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[15]. Limited salary and training constrain the ability of staff to provide person-centered care [3]. Low-cost policies lead to a decrease in staff numbers, high annual turnover, and burnout rates in care staff [16]. They impede the development of attitudes, stable relationships among staff and residents, and work methods that are vital for person-centered care [17]. Economization of care furthermore fosters a fragmentation of care professions [18] and institutions [19]. This fragmentation limits the responsibility for person-centered care to a small group [20]. However, person-centered care includes the entire social environment of the residents. Cost cuts restrict communication between staff and residents, which often consists only of instructions [1].

Communication barriers are the main factors impeding person-centered care [6]. Fragmentation of care professions obstructs information transfer. Empathically answering to needs of residents requires knowledge about their history, preferences, routines, and behavioral patterns [6]. Facility-wide communication of this knowledge is critical for person-centered care [6]. However, this information exchange often does not take place [6]. Knowledge transfer lacks openness, accuracy, timeliness, and systematics [21, 6]. Existing documentation systems lack information required for person-centered care [22, 23]. Accessible information is often outdated and too time-consuming to read [6]. Word of mouth techniques often lack consistency, accuracy, and do not propagate across different professions [6].

1.3. Distributed cognition

The theory of distributed cognition [24] can provide a model for reducing the communication gap in person-centered care. Knowledge of the preferences, needs, and personality of the person with dementia can facilitate person-centered care. Due to the fragmentation of care, this knowledge, however, is often distributed in small pieces among different caregivers [6]. Therefore, it is often difficult for caregivers to obtain personal information about the resident in time. Also, knowledge of supportive ways to communicate with the person with dementia can change rapidly over time as their condition evolves. A task that relies on information that is distributed in small pieces among individuals and that changes dynamically over time can be formulated as a distributed cognition task [24]. Thus, strategies for solving a distributed cognitive task might provide help to reduce communication gaps in

person-centered care. In other domains, computer-mediated communication proved to be a successful means of supporting distributed cognitive tasks (e.g., [25]). Notably, self-organizing knowledge management systems can support such distributed cognition tasks [26]. Self-organizing knowledge management systems foster the emergence of shared knowledge and the exchange of knowledge between users. All users cooperate and participate by adding and modifying information. In this way, the system collects distributed information and enables all users to use this information. In our case, users could use shared knowledge to engage in personal and supportive interactions with the person with dementia. In this study, we evaluate how self-organizing knowledge management systems can facilitate person-centered dementia care.

1.4. Information technology in person-centered care

Information technology can support different aspects of dementia care [27, 28]. Martins et al. [29], for example, used Facebook to exchange information among caregivers and significant others. Foong et al. [30] used information technology to facilitate communication between volunteer caregivers. However, existing technologies are not primarily designed to promote meaningful personal relationships between residents and caregivers. Also, systems to date do not address the identified hurdles of person-centered care.

1.5. Research question

We explored how self-organizing knowledge management affects the quality of person-centered care. We analyzed the potential and limitations of a collaborative communication system in a 6-month field study. After the test period, we conducted in-depth and focus-group interviews. We used the results to develop hypotheses and perspectives for interventions that might improve the quality of person-centered dementia care.

2. Method

2.1. Terminology

The study took place in institutional dementia care homes. We, therefore, use the term *caregiver* for formal, professional caregivers who are employees of the care homes and provide care services to the persons with dementia. We use the term *significant other* for people who are close to the respective

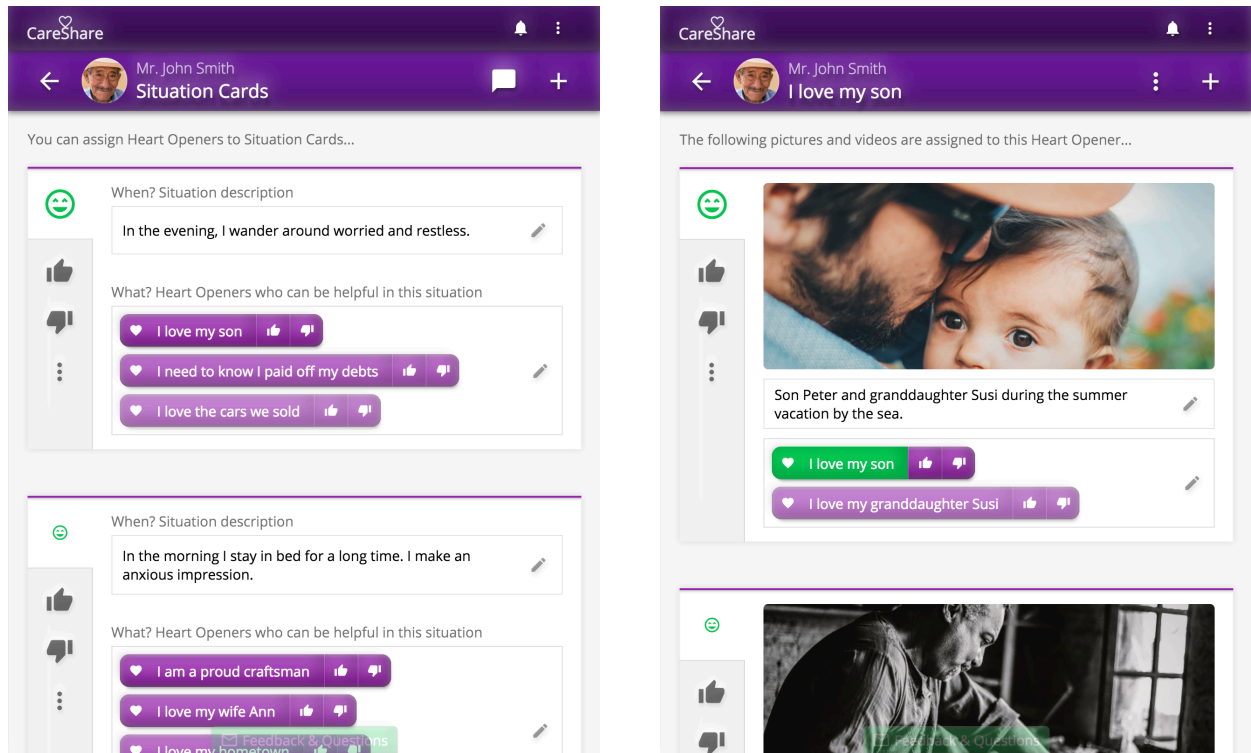


Figure 1: **Screenshots of CareShare.** A resident profile contains ordered situation cards (left). Situation cards link to heart openers. Heart openers contain ordered and annotated media files (right). Media files link to associated heart openers. Users can swap the position of situation cards, heart openers, and media files with their neighbors by touching the thumb up or down buttons. Users can edit content by touching the adjacent pencil button. Sample photos by Stephen Lustig, Ferenc Horvath, and Bobby Rodriguez on Unsplash.

person with dementia (children or grandchildren, spouse, and other relatives or friends).

2.2. Participants

We conducted the study in two German institutions for people with severe dementia. We recruited significant others of residents with severe dementia on facility-wide information events. Eight residents, eight significant others, and six caregivers participated in the study. All residents had severe dementia. We combined proxy and process consent. We obtained proxy informed consent from legal representatives of all participating residents. To maximize the ability of residents to participate in the decision of research participation, however, we additionally followed the model of process consent [31]: Before participation, significant others decided if participation reflected the values and preferences of the resident and if he/she would enjoy participating in the study. Caregivers and significant others then informed residents of their potential participation in the study in a manner appropriate

to their abilities and looked for signs of assent or non-objection. Caregivers and significant others assessed and verified ongoing consent throughout the study: they continuously looked for signs of refusal to participate in the study and, if identifiable, ended participation. Caregivers and significant others shared information relevant to the well-being of the residents with each other. The institutional ethics committee approved the study.

2.3. Intervention

CareShare is a collaborative communication system. The cloud-based application provides browser interfaces for mobile devices. CareShare aims to facilitate positive interactions between residents and caregivers. It dynamically provides personal information in a systematic and timely manner. It fosters self-organization among professional caregivers and significant others. The code is available as supplementary material.

2.3.1. Fictional usage scenario

In the evening, the resident John wanders around anxiously and restlessly. The caregiver Susi knows the family of the resident well. She tries to reassure John by talking to him about his beloved son. In the conversation, Susi tells John that the son is doing fine with the family business and that he already paid off all debts, there is no need to worry about that. This information brightens John up, and he calms down. In order to communicate John's reaction with her colleagues, Susi opens CareShare on her mobile device and creates a situation card for John (Figure 1). She describes the initial situation: "John wanders around in the evening. He seems anxious and restless." Susi then adds heart openers to the situation card. The heart openers communicate the topics that helped John to connect to Susi: "I love my son." and "I need to know I paid off my debts." She uses the messaging function to ask John's family to add pictures to these heart openers. The next day, family members add pictures to the new heart openers: pictures of John's son and grandchildren, and pictures from the well-working family business. They use the annotation function to describe what the pictures show and add relevant information from John's past. The other evening John again seems anxious and restless. Sam, a new caregiver, who does not know John, opens Susi's situation card in CareShare. He succeeds in engaging John in a warm conversation about John's family business. The proud and happy John tells stories about his business while they both discover the pictures and annotations in CareShare.

2.3.2. Knowledge retrieval

Person-centered care emerges from situation-specific individualized micro interventions [32]. The impact of such supportive interventions depends on their fit to the situation [33]. The data structure of CareShare aims to link situations to matching conversational topics that can guide supportive interventions. CareShare organizes information in an ordered tree structure (see Figure 2). When opening CareShare, authorized users access an individualized list of residents. Each resident profile comprises a list of situation cards and a group chat for associated caregivers and significant others (see Figure 1). The order of situation cards encodes their relevance for previous users. Situation cards have a textual description that summarizes observable cues of situations that benefit from person-centered micro-interventions.

Situation cards link to so-called heart openers. Heart openers provide conversational topics for individualized micro-interventions. Supportive micro-interventions increase the well-being of residents and decrease time pressure and job dissatisfaction among staff members [32]. Heart openers label emotional topics that are significant to the resident. These topics guide and enrich communication with residents. In this way, heart openers aim to foster personalized, meaningful interaction. The phrasing of heart openers is restricted to three predefined beginnings: "I am ..." for themes that stabilize a positive sense of the person's own identity; "I love ..." to indicate relationships and preference; "I need ..." to express needs and motives. This restriction ensures that heart openers reflect topics of identity, relationships, and needs: central values of humanistic therapies. The order of heart openers within a situation card encodes their prior effectiveness in the situation.

Each heart opener links to media files: images, videos, music, or texts. These media files facilitate communication about the heart opener and inspire engaging interactions. Annotations provide context information for the files. The order of media files within a heart opener encodes their prior effectiveness. Additionally, each file links to heart openers that are relevant to the file. This listing allows the user to access further heart openers that are associated with the corresponding media file. The order of this list of heart openers encodes their significance to the file.

2.3.3. Knowledge creation

The system aims to foster the emergence of knowledge through collaboration. Users can freely edit, create, and enrich content entities. Self-organizing systems require interpretations not to be comprehensive, complete, or precise to allow dynamic emergence over time [34]. The system distributes tasks to specialized individuals. Staff members integrate outcome information of interventions. Significant others enrich this information with personal material. Such collaboration improves the quality of the content [35].

Sharing outcome information about interventions improves the quality of person-centered care [32]. Users incorporate feedback about the effectiveness of content. Self-organization is highly feedback-driven [35]. Users linearly sort the content of situation cards, heart openers, and files by relevance. Users perform sorting by swapping adjacent items.

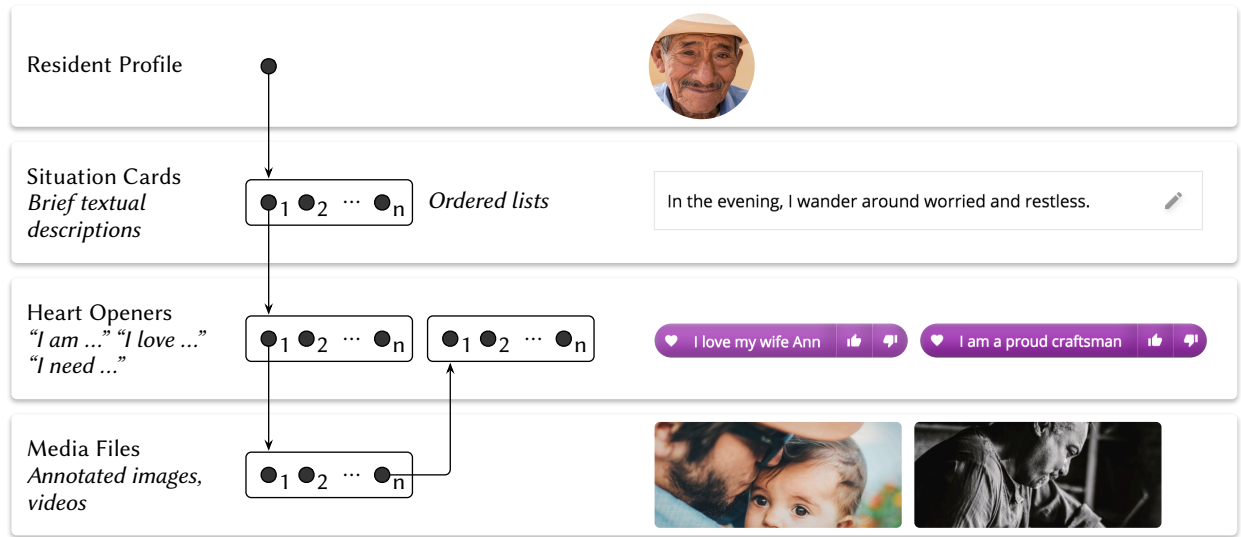


Figure 2: **Data structure of CareShare.** Resident profiles link to an ordered list of situation cards. Each situation card links to an ordered list of heart openers. Each heart opener links to an ordered list of annotated media files. Each media file links to an ordered list of heart openers. Users edit content and modify the ordering in each list. Sample photos by Stephen Lustig, Ferenc Horvath, and Bobby Rodriguez on Unsplash.

This bubble-sort approach requires a low cognitive load. Users can anticipate the effect of each sorting action.

2.3.4. Knowledge transfer

The system facilitates the flow of information and mutual awareness. These processes foster self-organization [34]. The system displays information in a compressed and concise form. Previous effectiveness determines the order of content. The system informs users about actions with an email notification system. For each resident profile, authorized users manage the access of other users of the resident information. The system allows for instant messaging between users.

2.4. Procedure

Professional caregivers and significant others used CareShare for six months. They freely chose how and when to use the system. Caregivers received tablet computers to access CareShare. We provided technical support.

2.5. Data collection

We conducted semi-structured in-depth telephone interviews after the six-month intervention period. The telephone interviews took between 30 and 60 min. Subsequently, we conducted semistructured

focus groups [36] in each facility. The focus groups included all participating significant others and professional caregivers. Group interviews encourage participation from people who are reluctant to be interviewed or feel they have nothing to say [37]. We aimed at identifying the effectiveness and costs of the intervention.

2.6. Analysis

We audio-recorded and transcribed all interviews and focus groups. We anonymized transcripts and checked them for accuracy. We used thematic analysis [38] to identify themes inductively.

3. Results

3.1. Person centeredness

Caregivers and significant others reported that CareShare increased personal communication with residents. Caregivers perceived an increase in the wellbeing of the residents after using CareShare.

“I heard your mother talking a lot more after I used CareShare with her. That was really amazing. There is a chain reaction [...] she became very eloquent again, which she usually is not.”

Caregivers and significant others reported that interaction often became more emotionally engaging.

“My mother comes out from behind her curtain. You don’t notice anything of the dementia anymore; she comes out completely.”

Caregivers reported that CareShare promoted relationship building. The information model facilitated personal communication. Heart openers helped elicit positive emotions.

“With heart openers we are very close to the people. Since the relatives are directly giving us the information, the patients react a lot more to what we say.”

Caregivers expressed that the individualized information proved helpful.

“CareShare helps me relate to a significant part of the resident’s life that we would not know and have not experienced.”

They indicated the importance of situated personal information for connecting to residents. Caregivers reported that CareShare helped provide a more comprehensive picture of the resident’s personality.

“[One part of the personality] is not accessible. And with the heart opener, we get access to this hidden part. And that is person centering that I do not reduce people to their shortcomings and illness, but that I see them as wholes.”

Caregivers and significant others reported that residents responded positively to the system.

“She said ‘I want one [tablet] like this, then I can always look at it.’ Because it reflects her memory [...] that she otherwise finds hard to get hold of.”

3.2. Bridging the communication gap

Caregivers and significant others indicated that CareShare helped them foster cooperation. They pursued a common goal that directly affected the well-being of residents.

“CareShare enables a role change of relatives and employees: doing things together makes an incredible difference for the quality of the relationship.”

Caregivers indicated that the quality of accessible information increased. Significant others put deliberate effort into creating high-quality content.

“I think distance creates closeness: with a little distance, completely different associations are awakened at home, different ideas are developed.”

Significant others developed more trust in caregivers.

“There is a great deal of turnover. Employees come and go. They don’t really know my mother. On admission, we were also asked about my mother’s biography. But that was just done once and never updated again. That’s why I find CareShare’s ability to update or add new information very important.”

3.3. Task satisfaction

Caregivers reported that CareShare increased self-efficacy and reduced helplessness.

“From the information, we could derive very clear instructions to act, which was quite easy to implement. It was also very nice to see that relatives had quite concrete ideas. That was really good for the residents.”

“It compensates the experienced helplessness. [...] You are on the same level because you look at things together and open up to them.”

Caregivers reported that CareShare helped them in building a relationship with the residents.

“CareShare helped gain the trust of the patients; I was very close to them. [...] I got to know some people a lot better because of CareShare.”

Caretakers expressed that CareShare reduces perceived task pressure. A larger group shared the responsibility for the content.

“Someone else is responsible for the content. That makes it easier for me as an employee. It takes away a lot of pressure.”

CareShare helped new employees get acquainted with residents.

“With CareShare, we have a tool in our hands that helps us train new employees.”

3.4. Well-being of significant others

Significant others indicated that with CareShare they were an active part of the care process.

“CareShare enables me to actively take part in the treatment. [...] This is a lot different from what I could do during a normal meeting with the caretaking staff.”

Significant others reported that CareShare strengthened their subjective feeling of connection with the residents. The significant others expressed that they integrate the care process into their everyday life, even if they live far away.

“Care Share is like a treasure chest for me. This makes it easier for me to interact with my mother. [...] That was the first time that I really thought about her [...] that was really cool, that I could help her like that.”

Significant others expressed more confidence that the residents are treated well.

“It is very positive to know that there are nurses who can deal with my mother’s topics. Because they have an excellent tool in hand which stores personal information.”

3.5. Criticism

Participants stress that access to information is not sufficient to guide interaction. A Caregiver reported that knowledge can lead to mistrust in the residents:

“The other side, however, is that we communicate behind the back of the resident. [...] The patient then asks ‘How do they know that?’ In the beginning, there is a certain mistrust. [...] At the moment I get all the information at my disposal, but how can I use it concretely and let it flow in?”

Participants expressed the concern that emotional activation could also induce restlessness:

“Talking to my father about these times almost caused nervousness because of his still existing curiosity, liveliness and restlessness. He wanted to go and play tennis, for example, as he had seen in the photos.”

Caregivers and significant others underlined the need for a notification system. They suggested a notification system that communicates with the software they use in their daily routine.

“I see the problem in the fact that the system must be operated actively in everyday life.”

System uptake required training and information.

“And at first it was too stupid for me because I didn’t know what to do. But then I understood it and was able to incorporate what I wanted to say.”

Significant others and Caregivers were concerned about data privacy and access management. Participants asked for a compromise between restricted access and flexibility.

“For me it is very important that I know exactly who gets the information and who has access.”

4. Discussion

The goal of this field study was to develop hypotheses on how to facilitate person-centered care in dementia care homes. We observed the use of a self-organizing knowledge-management system intended to fill communication gaps that might impede person-centered care [6]. We designed the system to enhance positive interactions between residents and professional caregivers and to facilitate cooperation between professional caregivers and significant others.

4.1. Main findings

Caregivers and significant others reported that CareShare facilitated personal communication and helped to engage in conversation with residents emotionally. Such communication, in turn, promoted relationship building. Caregivers reported that the application helped to provide a more comprehensive picture of the resident’s personality. These reports are in line with the assumption that empathically responding to the needs of residents requires knowledge about their personal lives [6]. Our reports strengthen the hypothesis that such knowledge facilitates person-centered care. Scaffolding describes the provision structure, guidance, and encouragement in person-centered care

[39]. A requirement for scaffolding is joint attention between the communication partners and a joint decision-making process [39]. Our results support the hypothesis that self-organizing knowledge-management can provide means to facilitate scaffolding during communication.

Caregivers and significant others also reported that CareShare helped to foster cooperation and increased mutual trust among themselves. These reports support the hypothesis that the quality of facility-wide communication and the openness and accuracy of available information is a critical requirement for institutional person-centered care [21, 6]. The reports are in line with the assumption that person-centered care is a distributed cognition task that benefits from dynamic systems to facilitate coordination among group members [24].

Caregivers reported that CareShare increased staff self-efficacy and reduced helplessness when interacting with residents. Significant others reported that CareShare increased their felt connectedness with the residents and their confidence that the residents are treated well.

Participants, however, also reported challenges in the usage of information technology in person-centered care. Emotion activation, in some cases, could lead to restlessness in residents, and knowledge about their personal lives lead to mistrust. System uptake furthermore required training and information. Participants also underlined the importance of data security when handling the data of residents.

4.2. Possible implications for practice

The distributed cognition perspective might provide a means of reducing hurdles in person-centered care

Critical knowledge for person-centered care is often not available for caregivers [6]. It is distributed over different significant others and caregivers. Hence person-centered care poses a distributed cognition problem [24]. Traditional documentation techniques do not solve this distributed cognition problem [6]. Based on our results, we hypothesize that self-organizing knowledge management is effective when applied in person-centered care. We propose to further investigate in decentralizing information organization in dementia care homes. Caregivers and significant others can contribute in their specific domain of expertise. We propose encouraging contributions in small increments. We assume that the knowledge base needs to allow permanent modifications to reflect changing

conditions. To date, traditional centralized means mainly remain static or costly to change.

Transferring content-maintaining tasks from caregivers to significant others might be beneficial for both

Self-organizing systems can transfer tasks from caregivers to significant others. These tasks include creating, updating, and ordering information. This transition decreases the workload of caregivers. It integrates significant others in the care process. Our results support the hypothesis that this integration increases the well-being of significant others and their sense of connectedness to the resident. Mutual trust and reciprocity seem to constitute critical requirements for collaboration among significant others and caregivers [40]. Based on our results, we hypothesize that collaborative efforts of caregivers and significant others can improve the quality of a shared knowledge base. We assume that a high-quality knowledge base, in turn, facilitates person-centered care. This assumption is in line with the observation that communication between significant others and staff facilitates care that honors the unique perspectives, values, and needs of each resident [41]. We observed that providing tools for collaboration can be beneficial for caregivers, significant others, and residents.

Situational features might guide person-centered interventions

Caregivers require information on a timely basis. During an interaction, caregivers have limited time to search and filter information. Hence, information has to match the current needs of the residents. These needs relate to objective situational factors as well as to the emotional state of the resident. Based on our results, we hypothesize that providing information about current needs is feasible with a minimalistic data structure: situational features link to emotional themes. Such data can encode collective, previous experiences and can dynamically accumulate experiences of caregivers and significant others. To date, traditional documentation systems do not provide such information.

4.3. Limitations

Participants volunteered to share their experiences. Opinions of the self-selected sample do not necessarily generalize to other significant others or caregivers. The sample may overrepresent a population for which collaboration among significant

others and caregivers is a priority. Nevertheless, the acceptance of our approach in this limited sample motivates the study of the broader transferability of the hypotheses generated.

We conducted interviews after the 6-month intervention period. We did not collect immediate feedback during the intervention. Feedback thus could be subject to positivity bias: participants may have favored positive over negative memories. Participants also might have attributed events to the intervention by coincidence. However, long-term commitment is crucial for the success of an intervention. We assume that our results reflect critical long-term effects.

We did not compare outcomes between different approaches. However, our results strengthen the hypothesis that self-organizing knowledge management qualifies to improve the quality of person-centered care. Comparative designs need to test this hypothesis.

4.4. Conclusion

Based on our findings, we hypothesize that self-organizing knowledge management presents an opportunity for reducing communication gaps in dementia care homes. Ekman et al. [5] propose routines that initiate, integrate, and safeguard person-centered care in daily clinical practice. “The registration of residents’ preferences, beliefs, and values must be considered equally mandatory as clinical and lab findings.” [5] We hypothesize that self-organizing knowledge management systems such as CareShare can assist in facilitating person-centered care. Such systems might assist in reducing the communication gaps in care settings, to increase the task satisfaction of staff, and the wellbeing of significant others. Based on our results, we hypothesize that such knowledge organization improves the quality of person-centered care. We hypothesize that self-organizing knowledge management systems provide the means to individualize dementia care in a context of increasing fragmentation and economization of care.

Authors’ contributions

DG and ML developed the concept. DG implemented the system. DG, JP, and JH conducted the interviews and evaluated the data. DG wrote the manuscript. JP, JH, and ML reviewed the manuscript. All authors approved the final manuscript.

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Andrea Jandt along with employees of St. Marienhaus Freiburg and Birgit Amelung along with employees of Seniorendienste Bad Wimpfen integrated the application into their workflows. They supported the field study. Birgit Amelung provided conceptual advice. She invented the heart openers. Beate Radzey from Dementia Support Stuttgart provided conceptual and coordinative support. The German Federal Ministry of Education and Research supported this work (grant number 16SV7322). This work is part of the first author’s doctoral thesis.

Conflicts of interest

The authors declare that they have no competing interests.

Summary points

What was already known on the topic:

- Person-centered care is an effective and popular humanistic approach for institutional dementia care.
- However, communication gaps impede the implementation of person-centered care in favor of routinized care.
- Self-organizing knowledge management can facilitate information flow.

What this study added to our knowledge:

- Self-organizing knowledge management might provide a promising tool to increase the quality of person-centered care.
- It might reduce communication barriers that impede person-centered care.
- Transferring content maintaining tasks from caregivers to significant others might be beneficial for both parties.
- Shared knowledge about situational features might facilitate person-centered interventions.

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