Stakeholder Perspectives on the Key Components of a Digital Service Platform Supporting Dementia - digiDEM Bayern

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Abstract. The increasing number of people with dementia and caregiving relatives will require a change in the provision of dementia-related services in the future. Digital technologies are a force for change. The new project digiDEM Bayern with its digital services on a digital platform and a digital patient registry should help to improve the situation for people with dementia and their caregivers especially in rural settings. An online survey among service providers for people with dementia and caregiving relatives in Bavaria was conducted to find out how they assess the current landscape of digital and non-digital service offers for people with dementia and their caregivers. The results of the survey have revealed that there is currently a large gap in the provision of digital services varying between the different categories surveyed. digiDEM Bayern addresses this gap with its digital dementia-related service platform.

Keywords. dementia, informal caregiver, stakeholder, digital, services, platform

1. Introduction

With 50 million people affected worldwide, dementia is one of the major challenges the healthcare systems are facing. Every three seconds, one new case of dementia occurs across the world. In Germany, 1.7 million people suffer from dementia, while there is one new case of dementia every 100 seconds. The figures for Bavaria (a federal state of Germany) speak of about 240,000 people affected by dementia [1], whereby it should be noted that a considerable number of unreported cases of dementia must always be expected [2].

The more people are affected by dementia, the greater is the burden on their families and the health system. Particularly in the early stages of dementia, care for people with dementia is mainly provided by family members serving as informal caregivers [3]. About 70% of those in need of care receive it at home from a relative [4]. Although

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caregiving can be a positive experience associated with a greater sense of purpose, satisfaction with life, higher quality of life, and higher self-efficacy, it is also associated with poorer physical and mental health outcomes [5], for example a greater risk of becoming depressed or an increased mortality rate. Besides the mental and physical burdens, providing care often takes a financial toll on the caregiving relatives [6]. For these reasons, the latter are called the 'hidden secondary patients'.

The research project 'Digitales Demenzregister Bayern' (Digital Dementia Registry Bavaria - digiDEM Bayern) was launched in January 2019 to improve the situation of people with dementia and their caregiving relatives in Bavaria effectively and sustainably. digiDEM Bayern is based on the results of the predecessor project 'Bavarian Dementia Registry – BayDem' including 363 people with dementia and 342 relative caregivers [7].

The two main objectives of digiDEM Bayern are: First, the acquisition of long-term data in a digital patient registry to help address significant challenges in dementia research, care, and policy; second, the improvement of the dementia care and supply situation especially in rural settings, due to the fact that there are still gaps in research related to technologically-based interventions with a focus on rural settings [8]. Therefore, digiDEM Bayern will provide digital services on a digital platform for people with dementia and cognitive impairments as well as for their caregivers. In addition, the digital platform is meant to support volunteers and interested citizens.

In order to identify detailed stakeholder requirements for the digital service platform, an online survey was conducted among providers of dementia-related services in Bavaria to determine which non-digital and digital services exist in the dementia service landscape and to identify gaps in service provision.

The objective of the study was to investigate the areas in which stakeholders identify the most serious deficits in the dementia service provisions landscape in order to then incorporate these findings into the further project planning of services of the digital dementia platform digiDEM Bayern.

2. Methods

We conducted an anonymous, cross-sectional online-survey across providers of dementia-related services in Bavaria/Germany. The survey was carried out during a two-month period from mid-May to mid-July 2019. Invitations to participate in the survey were sent via e-mail by the Bavarian State Ministry of Health and Care to their dementia-related network of service providers; it included a cover letter describing the aim of the study and providing the link to the survey.

In order to achieve the highest possible level of representativeness, this network of stakeholders includes inpatient and outpatient institutions, as well as administrative institutions, district offices and voluntary associations of all seven administrative districts of Bavaria. No incentive or reward was provided for completing the survey. A reminder was sent four weeks after the initial mail. For reasons of data protection, the personal data of the contact persons included in the mailing list are not known by the investigators.

The content of the online questionnaire was developed on the basis of scientific literature. It was accessible through the online SoSci Survey program (www.soscisurvey.de) as a 12-item questionnaire that covered the following three domains: 1. data about the service provider (7 items); 2. relevant data for a digital registry

(2 items); 3. assessment of the current supply situation with digital and non-digital services (3 items). The questionnaire comprised closed questions (response formats: Likert-Scale, predefined list of options or multiple choice).

In order to obtain a comprehensive overview of the service landscape in the dementia context and to be able to classify them into categories, we first conducted a literature research. The findings were then summarized in the following dementia-related service categories: information (simple provision of data), consulting (specific recommendation/advice), intervention (therapeutic or preventive measure), training (measures to learn or improve skills) and exchange (sharing knowledge and experience among users).

The questionnaire was pretested by five scientific employees with different background to make sure that the questions were clear and unambiguous. Furthermore, they assessed the questionnaire regarding its user-friendliness and potential technical problems. Adjustments were suggested and taken into account for revising the questionnaire.

3. Results

In order to achieve a reliable assessment, our aim was to get about 100 responses through the online survey. In the end, a total of 97 stakeholders returned valid questionnaires.

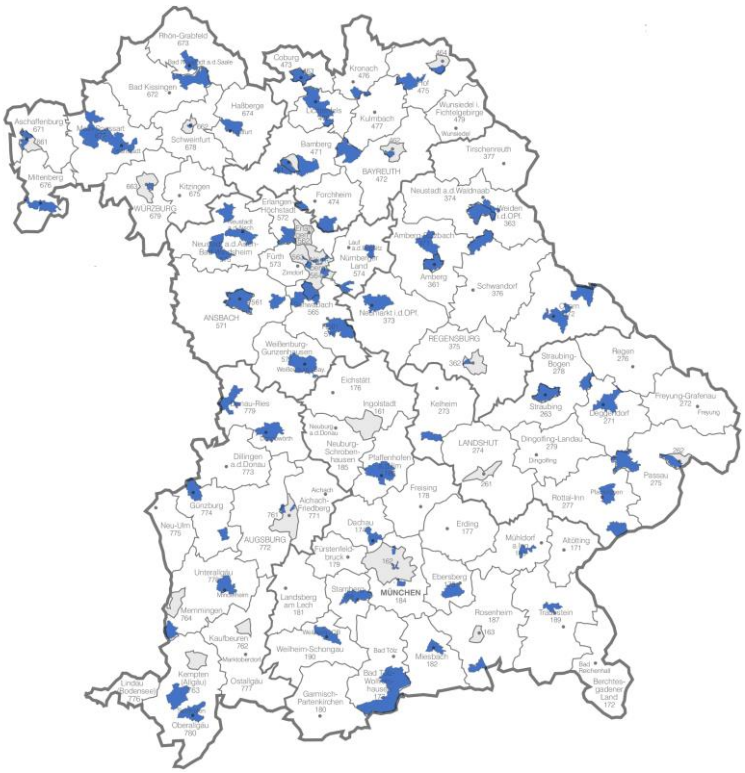

Figure 1. Map of Bavarian administrative districts – location of the participating stakeholders (postal code).

The participants were asked, in which type of institution they offer their services (multiple answers were possible). Thirty-four percent of the respondents reported to provide their services in an outpatient environment (medical practice, outpatient care, memory clinic), while 46.4% did so in an inpatient environment (hospital, rehabilitation facility, nursing home, day clinic, dementia residential community, day care), 26.8% in an administrative environment (municipal, city or county administration) and 41.2% in other environments (center for caring relatives, Alzheimer societies).

Figure 1 illustrates that the survey participants are distributed all over Bavaria and cover both urban and in particular rural areas, where the service coverage for people with dementia and their caregivers is usually rather poor. The classification of all participants' locations in urban and rural areas is based on the settlement structure determined by The Federal Institute for Research on Building, Urban Affairs and Spatial Development (BBSR).

A main part of the survey was the participants' assessments of the current landscape of dementia-related services in Bavaria. Services in the field of dementia can be provided either digitally or by the classical non-digital means, such as paper-based or personal. For this reason, the following question was asked: How do you assess the current situation of service provision in the different categories regarding non-digital and digital dementia-related services in Bavaria?

Figure 2 shows the results of the assessment, differentiated by the category and type of service delivery (non-digital and digital).

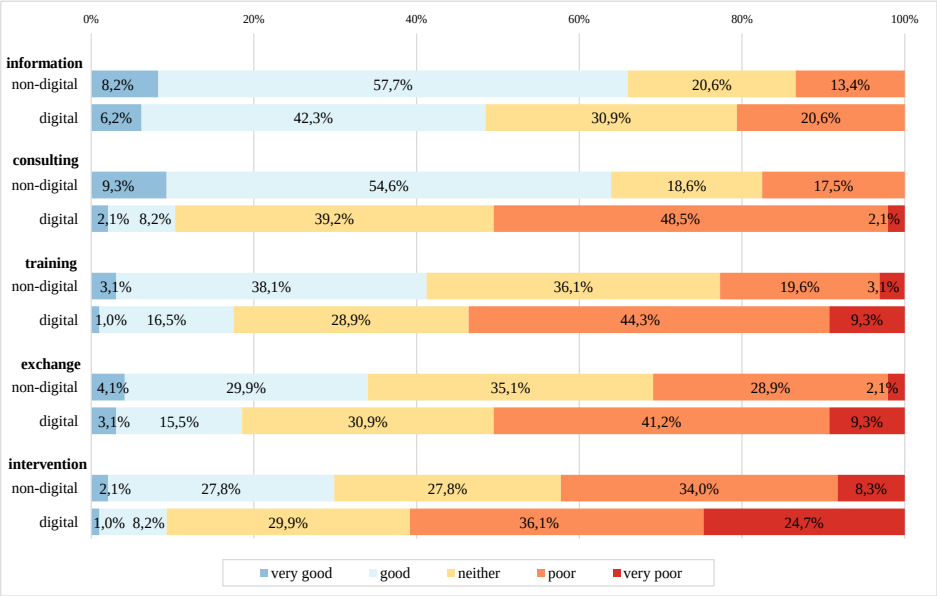

Figure 2. Assessment of the dementia-related service offers by category and type of provision (n=97).

As can be seen, in each category, the provision of non-digital services is considered to be better than the provision of digital services (in particular regarding ratings as good or very good). It is also remarkable that there are only two categories overall that are

rated as at least good by more than 50% of the participants: the provision of non-digital information (65.9% in total) and non-digital consulting (63.9% in total). Furthermore, no category of non-digital or digital service offers was rated as very good by more than 10% of the participants. In fact, the provision of services in the category of non-digital consulting (9.3%) and non-digital information (8.2%) are still rated best here.

In general, the digital service landscape is rated worse than its non-digital counterpart is. Within the digital services' categories, only digital information was rated good/very good by 48.5%, while all other categories are below 20%. Looking at the provision of digital offers, the categories digital consulting (rated as good or very good by 10.3% in total) and digital intervention (rated as good or very good by 9.3% in total) came off worst in the service landscape. With the exception of digital information (20.6%), the remaining categories are considered as poor or very poor by more than 50% of the participants (digital exchange 50.5%, digital consulting 50.6%, digital training 53.6%, digital intervention 60.8%).

4. Discussion

The objective of the present study was to identify the stakeholders' perspectives on the digital platform with service offers, one of the two pillars of the digiDEM Bayern project.

While most of the current research focuses on the perspectives of those directly affected, i.e. people with dementia and their informal caregivers, this study analyses the perspectives of the people and institutions who provide services for people affected by dementia. As different stakeholders can assess the value of and benefit from digital services in different ways, it is also important to consult this group of stakeholders while setting up a digital platform with digital services. These stakeholders are very familiar with the current situation in the service landscape for dementia. This is possible, on the one hand, due to their immediate provision of services on site, and on the other hand due to the networking of these stakeholders among each other, e.g. at the annual Bavarian Dementia Day or the Bavarian Dementia Week with more than 600 active participants.

Even though digital technologies can play a major role in health care by helping to create new patterns of communication, empowerment and engagement [9], it became clear from the survey results that in Bavaria, there is still much to be done in the dementia digital services landscape.

Besides not knowing about the existence and the availability within a reasonable time, structural aspects (e.g. distance, finances) are often cited as barriers for using non-digital services [10]. The availability and accessibility of stage-specific service provision at the right time and at the right place cannot be underlined enough. Since digital services are independent of opening hours, location and the limited number of health care providers, offering a digital provision of health services by using an online platform has advantages especially in rural settings [11]. digiDEM Bayern also focuses on dementia care in rural settings, in order to investigate care and services in different geographical regions with different demographic, socio-economic and structural characteristics [12].

It is obvious that as dementia progresses, people will be less and less able to access digital services. However, people with dementia are usually supported by a caregiver, typically a spouse or an adult child, who can still benefit from digital services. According to current studies, the number of internet users in Germany aged 60 to 69 years was 85% and almost 60% of those aged 70 years or older [13]. This implies that the affected group can still benefit from the digitalization of dementia-related services.

Internet and social media such as Facebook are increasingly being used by older people to find health information and to exchange information among each other [14]. In contrast to that, only 18.6% of our study participants rated digital services in the context of exchange as good. Hence, our findings suggest that the need for a digital platform such as digiDEM Bayern on which also sensitive health data can be exchanged between those involved is very high.

Especially in the field of interventions, which performed worst (with 9.2% in total giving a good or very good rating), there is a great potential of improvement. Numerous studies have shown that the burden on family caregivers is strongly linked to outcomes of the caregivers themselves but also the people with dementia who need care [15]. The effect of digital interventions has meanwhile been proven in various studies [16]. Based on the results of Pendergrass et al. [17] digiDEM Bayern will provide a digital intervention on its platform to measure the caregivers' subjective burden. The results will be presented in the form of a traffic light system related to physical and mental health and provide subsequent recommendations.

The same applies to the category of digital training (rated as good or very good by 17.5% in total), which has been proven to be effective for instance in the form of e-learning [18]. By providing also a digital navigator with individually tailored information services and evidence-based digital interventions on a digital platform, digiDEM Bayern seeks to reduce the gaps in the categories of information, consulting and intervention in the digital service landscape as well.

A limitation of the study is the recruitment of survey participants via a third party (Bavarian State Ministry of Health and Care). Therefore, it cannot be guaranteed that all service providers in Bavaria had the opportunity to participate in the survey. Nevertheless, the evaluation of the survey participants showed a good distribution of different service provision sectors and a good regional distribution of urban and rural areas with different old-age dependency ratios.

5. Conclusion

Digitalization can improve health care and research on health outcomes and thus help closing the identified gap between non-digital and digital service provision. As to our knowledge, digiDEM Bayern is a digital patient registry and a digital service platform that - with its digital project architecture based on the two combined digital pillars – is unique in the field of dementia research.

By involving the stakeholders' perspectives and expertise at the beginning of the project, i.e. in the planning and developing phase of the digital support platform, we increase the probability of a successful implementation and enhance the benefits and value of named platform. digiDEM Bayern can thereby make its contribution to the digital future of dementia health and care especially in rural settings.

Acknowledgements

The research team acknowledges the support of the Bavarian State Ministry of Health and Care (StMGP) with the recruitment of the participants, and is grateful to all the participants who took part in this study. digiDEM Bayern is funded by the Bavarian State Ministry of Health and Care under the Funding Number AZ G45d-G8300-2017/1606-

83. The views expressed are those of the authors and do not necessarily reflect those of the StMGP.

The present work was performed by Michael Reichold in (partial) fulfillment of the requirements for obtaining the degree "Dr. rer. biol. hum." from Faculty of Medicine of the Friedrich-Alexander-University Erlangen-Nürnberg.

Statement of Ethics

This survey was approved by the Ethics Committees of the Faculty of Medicine of Friedrich-Alexander-University Erlangen-Nürnberg (158_18 B)

Disclosure Statement

The authors have no conflict of interest to declare.

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