

A Mobile Application for Supporting Dementia Relatives: A Case Study

Till HALBACH^a, Ivar SOLHEIM^a, Siri YTREHUS^{ba}, Trenton SCHULZ^a

^a*Norwegian Computing Center, Oslo (Norway)*

^b*Western Norway University of Applied Sciences, Førde (Norway)*

Abstract. This work presents DILP, a project and solution for caregivers and relatives of persons with dementia. The app aims at providing help on demand and covers topics like medical and psychological issues, communication, legal and financial issues, practical advice for everyday challenges, and more. The technology is explained in detail, and special attention is given to the user-centered development and content authoring. The final solution was tested in the field by relatives of persons with dementia and health workers with many encouraging results regarding usefulness, usability, structure, and others. However, the trials also showed that functionality like search and find-ability of information was difficult to achieve.

Keywords. Micro-learning, on demand, just in time, personalization, universal design

1. Introduction & background

Relatives of patients affected by dementia face many challenging situations in their everyday life as the illness progresses. In Norway, municipalities typically offer evening classes / courses to meet the needs of relatives. The main goal of these classes is to inform about the illness, give advice regarding caregiving, and improve life for caregivers (Liddle et al., 2012; Mary S. Mittelman, Haley, Clay, & Roth, 2006; M. S. Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Nunnemann, Kurz, Leucht, & Diehl-Schmid, 2012; Schulz et al., 2002). The classes however are typically held only twice a year at specific times, so there is the need for a solution which makes the information available in a ubiquitous manner, more in an on-demand style.

It is estimated that there are between 80,000 and 100,000 people suffering from dementia in Norway (Folkehelseinstituttet, 2018). This amounts to an estimated 300,000 relatives of dementia patients (Folkehelseinstituttet, 2018), or roughly 5% of the population. Worldwide, roughly 50 million people are living with dementia in 2017 (Alzheimer's Disease International, 2018). All given numbers are expected to grow considerably as the number of dementia patients is expected to double every 20 years (Alzheimer's Disease International, 2018). Dementia relatives experience major changes in live and have to handle many new and often quite challenging situations, resulting in demanding mental and physical strains.

In the DILP Project – Digital Learning Arena for Dementia Patients' Relatives, a mobile application was developed with a digital version of the course with the aim of helping relatives to cope with their changes in life, to provide advice in stressful

situations and busy schedules, and in general to ease the burden. The app is the project's main deliverable, as currently there is no such digital solution in Norway. The project lasted from 2014 to 2017. Consortium members were research institute Norwegian Computing Center, Diakonhjemmet høyskolen, e-learning company Conexus, interest organization Seniornett, and the municipalities Kristiansand, Røyken, and Aurskog-Høland.

The paper's contributions are the discussion of considerations during the app's development and the analysis of results from focus group and field trial, including a summary of lessons learned. It is organized as follows. The employed technology is presented in detail first, upon which the focus turns to authoring of content. Then, we detail the field tests and discuss the results, before the conclusion is drawn in the end.

2. Mobile app

Our solution is based on the mobile app mYouTime (Conexus, 2018). The app is available for Android and iOS operating systems and thus both tablets and smartphones, but there also is a web interface.

mYouTime offers a number of advantages over an ordinary evening class: First, its content is available on demand (as soon as it is installed), so there is no need for caregivers to wait until the next available evening class in case urgent questions might arise. Second, the app offers a great wealth of accessible media types such as text, formatted/rich text, including hyperlinks, as well as subtitles, images, videos, and audio/speech, both in stand-alone and compound form. Content can therefore be presented in multiple modalities and thereby universally designed, and it can be enriched with for instance demonstrating videos, illustrations, as well as audio comments. The app's content resources are indexed/tagged with regard to modality, target group, complexity, geographical region, and topic. The app can thus, together with its search functionality, be used as an indexed look-up resource, which allows swift access to the information needed. This mechanism is central to the app's personalization capability. Content browsing is of course possible, too. We have chosen the following target groups according to the individual's relation to the patient: "Children", "grandchildren", "partner", "sibling", and "friend". An additional tag is "professional caregiver", such that the app is suitable to train health workers as well, as asked for in related research (Brodaty, Thomson, Thompson, & Fine, 2005). Complexity tagging includes the categories "basic", "exhaustive", and "easy". The first compounds of regular (brief) content, while the second is used to tag extensive and lengthy information. The third tag is reserved for content with high comprehensibility, such as for children. Tagging of geographical regions is useful to limit the validity of content for instance to specific municipalities and counties. The list of topic tags consists of the high-level tags "what is dementia", "communication", "change in behavior", "everyday help", "environments and society", "legal and financial aspects, rights", "relief", and "hospital", as well as a number of sub-level tags under each high-level tag.

The app can also be used as an authoring tool to supply additional and updated information by, for example, recording video or audio. A municipality's dementia coordinator can thus be given author privileges, while most caregivers and relatives

will have the status “information consumer” and thereby be permitted to access content only.

The app’s content is organized in learning units or lectures. Each lecture consists of consecutive slides of one of the available templates, which includes “text”, “text & image(s)”, “text & audio”, “text & image & audio”, “text & image & hyperlink”, “video”, “image”, and “(multiple-choice) quiz”. The entire format encourages shortness and to-the-point information, thereby facilitating micro-learning. Therefore, there are strict limitations with regard to number of characters for titles, captions, texts, and similar, as well as restrictions for video and audio lengths (in terms of file size), giving the app a Twitter-like appearance. The hyperlink slide was used for extensive information and simply links to web pages on an external web server, and for content that needs frequent updates, such as contact information, meetings and events, news, etc.

2.1. Topic research, content production & requirements work

The learning units were developed by the academic community at Diakonhjemmet and Western Norway University of Applied Sciences without accounting for the final format. For this, the authors surveyed the available literature and research, and complemented with findings from their own focus group interviews (elaborated on below), thereby giving a virtually complete coverage of the area (Skillen et al. 2012). The work started with a coarse categorization and continued with filling in the gaps and adding more details later on. The raw text was converted into learning units by dividing the material into successive slides but without splitting sentences. This process was further influenced by the aforementioned text length limitations and semantic considerations to keep logical pieces of content intact.

A lecture always starts with a title slide, which sets the topic and contains the learning objectives. Illustrative images have been inserted between many consecutive

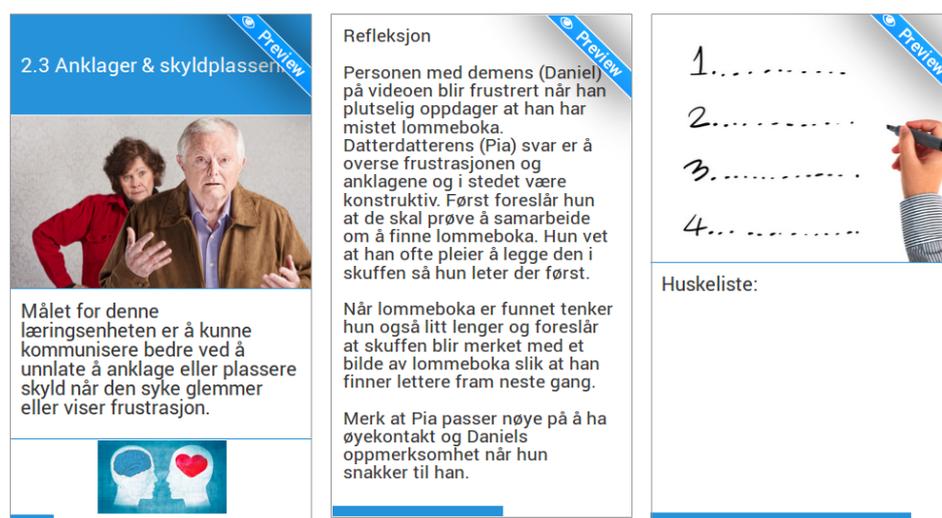


Figure 1. Screenshots of single DILP lecture slides: Title/goal (left), Reflection after a video (middle), and Takeaways at the end of a lecture (right)

text slides to make the information more “digestive”. A lecture always ends with a short take-away list of main points. Also, a video is always followed by a slide with a short summary of its content, and with the discussion of considerations that invites self-reflection. Title, reflections, and takeaways all have the same consistent layout for easier navigation, as illustrated in Figure 1. Audio production started when all slides were defined. Some lectures have no speech at all, others are accompanied of text read partly by synthetic voice, Olav from acapellabox (Acapela Group, 2018) and Nora from MacOS, and partly by human voice.

Videos were produced for a target duration of roughly one minute. Planning started with writing of dialogs and definition of message and story. A storyboard defined scenes, as well as camera and microphone positions. Afterwards, the recordings were clipped, captions were added, and they were finally scaled down to go under the maximum allowed file size, which was a technical limit only. The main aspect for the file size was the video duration.

In total, the production of content was quite costly (even though we do not have exact numbers to prove this claim), including topic research, production of video, subtitles, audio/speech, and images. It is hence crucial that the raw material is as mature as possible before the transition to the final format in order to avoid re-production of content.

2.2. Initial focus group interviews

The aim of the focus groups was to provide basic information and input for the process of defining the functional and technical requirements for the DILP service. The focus groups were carried out in all three municipalities by means of interviews and questionnaires. In total 13 informants participated with varied relations to the person with dementia: Spouses, siblings, sons and daughters, grandchildren, and friends. A great deal of attention was dedicated to documenting the participants’ personal experiences, the daily challenges in the relation with the person with dementia, views and expectations towards the final solution, and suggestions for content and content areas.

The focus groups identified the following main areas to be covered:

- medical and psychological issues,
- how to communicate with persons with dementia,
- legal and financial issues,
- practical advice for everyday challenges, and
- collaboration with the municipality and related health services.

The groups also provided a number of recommendations for the service and how it should be designed:

- A Web based alternative to the offerings from the municipality
- Provision of just-in-time help – when and where the need occurs
- Personalized information to meet the different needs and competence of the relatives
- Organization of information according to specific categories, user groups, level of competence, and knowledge
- Target particularly on everyday challenges, e.g communication, coping with behavior issues and similar
- Provision of multimodal information, in particular short videos were asked for

- Zooming in on the first phase of the progress of dementia, when the need for this kind of information is particularly important

Based on these and other requirements, the app was developed accordingly and evaluated in the field tests. Inspiration and ideas were also taken from related literature, such as (Burns et al., 2012; Ducharme et al., 2011; Halbach & Schulz, 2013; Hepburn, Tornatore, Center, & Ostwald, 2001; Kangas & Kinnunen, 2005; Leung, Findlater, McGrenere, & Graf, 2010; Pinquart & Sörensen, 2006; Rosness, Haugen, & Engedal, 2008; Samia, Hepburn, & Nichols, 2012; Thinnes & Padilla, 2011). The discussion of related work, though, is outside the scope of this paper.

3. Field tests

The app was developed in 2015-2016 and afterwards tested in the field. In total, 17 participants were recruited for the trials in three municipalities on a voluntary basis. All were either relatives for dementia patients or working with dementia-related aspects in a municipality. The user group had a large age span, from below 30 to over 80 years, with the majority over 50. Some of the participants had also taken part in the first focus group. The participants were asked to download and install the app, login with readily provided credentials, and to simply explore app and content while filling out a digital questionnaire (five-level scale) with their opinions and thoughts.

We experienced a low response rate of 37% or only seven respondents. Also, three participants spread the answering process over several days, and we assume that participation was too much a burden for the already tight regular schedule of dementia relatives. On the other hand, those who participated were highly dedicated and contributed with a quite thorough walk-through of the app.

The informants were satisfied regardless the duration of lectures, with the exception of municipality-relevant information, which got a lower-scale evaluation. This is interpreted such that there is no optimal length. Rather, content and appearance have a bigger impact on how duration is experienced by the users. This applies in particular for municipality content, whose rating correlates with that for experienced usefulness.

All lectures were rated as being clear and comprehensive (partly agree and entirely agree), except for a single informant who checked “partly disagree” and “entirely disagree” for a whole range of lectures, in sharp contrast to the other answers, without any further comments. The lectures were judged as being “quite relevant” and “very relevant”, again with the exception of municipality content, which got lower scores. The recorded comments reveal that content and design of the web page (which were under control of the project) were part of the informants’ judgments. Along the same lines, the usefulness of the lectures was experienced as “quite useful” to “very useful”, except for a particular lecture which got a neutral rating with the comment that its content was “too theoretical and not possible to accomplish in practice”. For a few participants the content was known from before, which resulted in a lower rating usefulness rating than what was the case in reality.

Audio/speech versions of text was viewed with neutral eyes. Particularly one informant commented on an unfamiliar machine voice and a “sharp voice” in videos, which is most likely due to a quite high compression rate for audio in videos. High-quality speech synthesis is advisable instead of the low quality that often comes with

free and open-source tools. Another comment mentioned a poor pronunciation of medical terms with artificial voices, which is a real problem in many low-level text-to-speech solutions. Here, an accurate specification of the pronunciation of unusual words would help.

The informants found the videos to be (quite and very) useful and commented on “too few” in their comments. In fact, a more hands-on character of some lectures in form of examples and practical advice was requested. However, also realism was asked for, as one of the patients in the video was “too easy to distract”.

It was a known issue that the 23 lectures were not covering the entire area, and this was also remarked on with several participants mentioning missing topics and in-depth information. We think a user interface that allows to comment and discuss the given information would be useful here.

The informants found the structuring of lectures, including basic and extended versions, takeaways, and local information (quite or very) useful and gave the same judgement for the “Getting started” lecture, and the fontsize. Quizzes and “text to speech” got a neutral rating, and one particularly critical person pointed to what she viewed as bad grammar and poor language. While we do not agree with this sentiment, it is clear that a language and grammar check should always be applied before releasing learning content to the public. Neutral was also the judgement regarding how to navigate the app, how to search for and find content. Although there were no further comments, we believe this is due to the organization of lectures in a mail-like fashion, inbox and archive and such, which does not feel suitable in this context.

3.1. Final focus group interviews

The field evaluation was complemented by focus group interviews in two municipalities with in total nine participants, partly overlapping with the recruitment from the first focus group and field trials.

In general, the informants were satisfied with the app and found it quite useful. The structure of learning units / lectures worked very well. When it comes to content, the participants (including health workers) liked videos in particular, but also the self-reflection prose related to these because the text was inspiring and resulted in a more efficient learning experience.

Another finding is that it is useful to distinguish between basic and in-depth information. It was convenient for the participants to read the short basic information first and, if needed, to look more closely at in-depth material later on when there was more time. Several persons also commented positively on the information designed for and aimed at children, but also advised that children should have easy access to all other types of information in the app, too.

We had set the font size to values larger than what is usual in apps of this kind, and the participants liked this because it made, as they said, the app more accessible. Also the limited amount of text per page and short paragraphs worked very well for these participants.

The reading aloud option was generally viewed as less successful. Some said they did not need this option, others found the (computer) voice too monotonous and hard to follow.

Most of the participants found the quiz option less attractive. The option might be useful for children, they commented, but advised to remove it from the app.

The informants recommended more local information, but at the same time they desired this to be easily available in the app rather than to be redirected to the municipality's web page.

4. Conclusion & outlook

We have presented DILP, a project and solution/app for caregivers and relatives of persons with dementia. We explained the technology in detail and dedicated special attention to content authoring and the formulation of requirements. The final solution was tested in field trials with encouraging results.

The user-centered development process with several iterations and an early focus group interview lead to a high degree of user satisfaction, and a high rating of the experienced usefulness of the app. The users also gave a good ranking of the structuring of content. The most important takeaways here are that the right type of content and a good design/appearance impact the user experience more than the duration/size of learning units, even though short and highly comprehensive lectures are explicitly appreciated. Lectures should be as practical and close-to-reality as possible. To achieve this, the use of examples is highly beneficial, and particularly videos (with a duration of less than one minute) are recommended. The evaluation however also showed that particular functionality like search and find-ability of information was difficult to achieve. Here, more research is needed to develop a more appropriate solution.

Other than that, the app constitutes nearly production level maturity. Currently, we plan to add more lectures as requested, and we are working on the proper business model for the successful deployment in Norwegian municipalities. However, we have also been discussing the relevance for other European countries and are looking for public and private actors interested in a future cooperation.

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