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Experiences with searching for information on precautionary documents on the internet

An important area of health care is advance planning for medical emergencies, which can be regulated individually by precautionary documents. Precautionary documents such as living wills and powers of attorney can be drawn up by all people of full age and are very well known among the population, but are still little represented in the younger age groups (IfD Allensbach 2014). The topic is complex and addresses medical, ethical and legal aspects. There are also misconceptions about precautionary documents. This can contribute to fear of contact and prevent careful individual provision for an emergency. Even in samples where high prevalences of existing precautionary documents are found, uncertainties are cited with regard to their precise preparation and application (Elmeadawy et al. 2017). The internet is an increasingly important source of information for citizens on health issues.

Summary

A large proportion of people use the Internet to obtain health information. Numerous digital information offers can also be found on precautionary documents, which are a significant possibility for planning ahead for illness and treatment situations. Within the framework of a cross-sectional survey on precautionary documents in the Würzburg region, 240 people were asked about information searches on the internet and their experiences with precautionary documents. The majority of respondents (67%) had already searched for information on precautionary documents on the internet. The experiences are related to age and knowledge about precautionary documents. The group of adults over 65 years of age is particularly striking, as compared to other age groups, they unexpectedly often use the internet to search for information on precautionary documents (85%) and tend to report more positive experiences. Searching for information on the internet plays a central role in the area of precautionary documents and also affects older population groups. The divergent experiences with digital information search in different subpopulations raise the question of how to promote a well and, above all, properly informed citizenry in the digital age.

Keywords

Digital information seeking, living wills, advance care documents, health information

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>> According to a representative survey, around 2/3 of citizens in Germany specifically search for health information on the internet (Schaeffer et al. 2021). There are also various digital information offerings on precautionary documents, including websites of ministries and private organisations, health portals, forums and communities, with varying information quality and user-friendliness (Stuart 2017). A British study that assessed the quality of online information on advance directives using several measurement tools found that only one of 34 websites analysed met the criteria of suitability, user orientation and effectiveness (Stuart 2017). This poses particular challenges for readers who need to assess the information at hand. Studies on digital health literacy show the difficulties in assessing health information, especially the trustworthiness and neutrality of information in the digital space. Older people (86.0%) and people with chronic conditions (77.1%) report greater problems in this regard (Schaeffer et al. 2021). Precautionary documents have a particularly high relevance for these population groups due to the more frequent occurrence of medical emergencies in old age.

So far, the use of online information on precautionary documents has hardly been researched. Due to the increased importance of (information) offers on the internet, it can be assumed that also in the area of precautionary documentation , the internet plays an important role in obtaining information and that there are difficulties in assessing the information found.

Research questions

The data are part of a larger study on the state of knowledge about advance care documents in the city and district of Würzburg (Fleischmann et al. in peer review). The present evaluation focuses on the following questions: 1. To what extent do the respondents use online information on precautionary documents?

What information are they looking for? 2. how do respondents experience their own search for information on the internet?

Method

The data collection took place within the framework of a non-representative cross-sectional study via questionnaire (online and print) in the region of Würzburg/Mainfranken between July and December 2021. Citizens aged 18 and over were included according to practical accessibility (convenience sample). Informed consent was obtained from participants before the survey began.

The survey was advertised via social media (Instagram, Facebook), local newspapers, magazines and promotional flyers, as well as disseminated via senior citizens' advisory boards of the municipal company.

Data collection was completely anonymous. Obtaining an ethics vote was not necessary (correspondence with the Ethics Committee of the University of Würzburg, AZ 20201117 01).

Survey instrument

The entire questionnaire consisted of 71 items (Fleischmann et al. in peer review), at the end of which there was a section on internet searching, which formed the basis for the present evaluation. The objective level of knowledge of the respondents was recorded in the main part of the questionnaire with 34 questions on the type, purpose and use of precautionary documents. A sum score with a maximum of 34 achievable points was formed from the number of correct answers.

The first section on internet search recorded the use of the internet to search for information on precautionary documents (‚Have you ever searched for information on precautionary documents on the internet?' with the answer categories ‚yes' and ‚no') as well as

the type of information that was searched for (‚What information on the topic of precautionary documents have you ever searched for on the internet?'). Six closed answer categories with the most frequent search options as well as a free text field for further answer alternatives were offered.

This was followed by four items on the experience of searching for information on the internet, based on the German translation of the Information Seeking Experience Scale (Baumann et al. 2020). These related to finding information (‚I was able to find the information I needed without any problems'), frustration (‚The search for information frustrated me'), information quality (‚I was worried about the quality of the information') and the comprehensibility of the information (‚I could easily understand the information I found'). This was followed by an item on general satisfaction with the search result. The items were rated on a 4-point Likert scale from ‚disagree' to ‚agree'. Due to a programming error, the item on finding information was excluded from the analysis and not evaluated further.

The analysis was primarily descriptive using IBM SPSS 28.

Sample description

Figure 1 shows the sample development for the different sections of the survey. The completion rate for the entire questionnaire was 10.1%. For the additional module of information search on the internet as well as the experiences made in this context, there were no missing values for the evaluation.

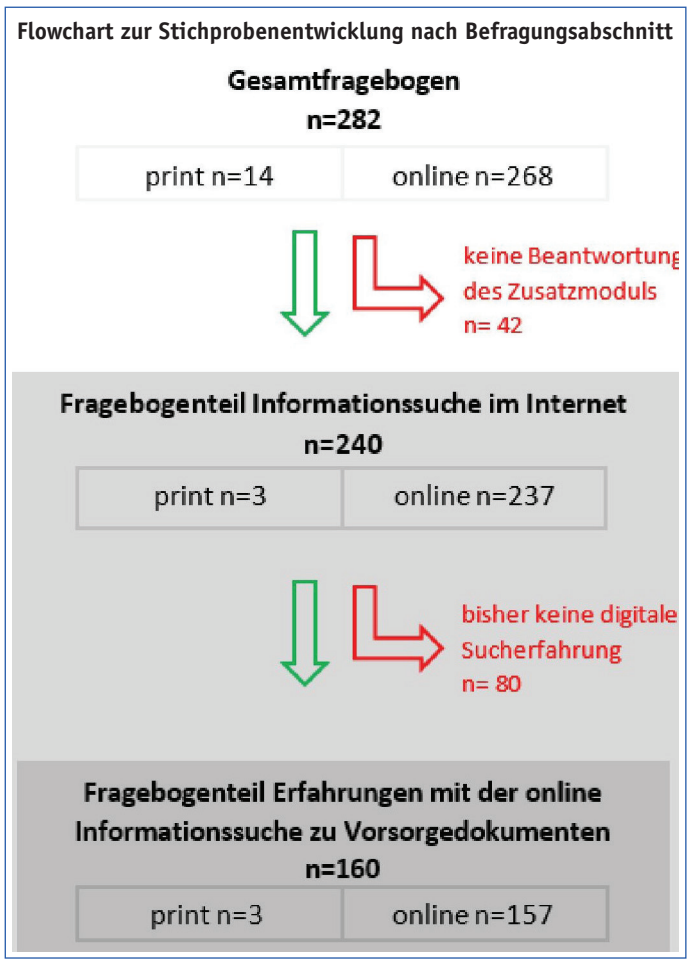


Fig. 1: Flowchart on sample development by survey section.

The 240 respondents who answered the last section of the survey were between 19 and 83 years old (MAlter= 50.3 years, SD = 15.4). The socio-demographic characteristics of the sample are presented in Table 1. The level of education in this study was defined by the highest school-leaving qualification attained. A large proportion of the respondents have a precautionary document (142/59.2%). Out of a maximum of 34 points to be achieved in the knowledge test on precautionary documents, the respondents achieved an average of 22 points (SD = 4.4, range 4 to 30).

Results

Searching for information on the internet

For a large part of the respondents, the internet is a potential source of information on precautionary documents. 155 respondents

Stichprobenmerkmale	
	n (%)
gesamt	240 (100%)
Geschlecht	
weiblich	151 (62,9%)
männlich	85 (35,4%)
divers	0 (0%)
Altersgruppe	
18–34	54 (22,5%)
35–49	51 (21,3%)
50–64	88 (36,7%)
65+	47 (19,6%)
Bildungsniveau	
niedrig	5 (2,1%)
mittel	164 (68,3%)
hoch	71 (29,6%)
Besitz Vorsorgedokument	
Ja	142 (59,2%)
Nein	97 (40,4%)

Tab.1: Socio-demographic characteristics of the sample.

(64.6%), when asked about the media used to search for information, stated that they would consider searching via a free internet search. The websites of official institutions such as ministries come into question for 178 (74.2%), especially frequently for people with a high level of education (65/ 91.5% of all people with a high level of education). Non-digital information sources such as information brochures/guidebooks from bookshops or magazine articles were mentioned less frequently as potential sources of information (106/44.2% and 66/27.5% respectively). While the young adults aged 18-34 showed clearer preferences for digital offers (only 1/1.9% did not consider digital offers), the older adultsover 65 chosethis less frequently (11/23.4%). No significant gender differences were found.

When asked about their actual search behaviour so far, 160 (66.7%) stated that they had already searched the internet for information on precautionary documents. The proportion of persons who stated that they had used the internet to search for information increased with

age (rpb=.310, p < .001). While only 24 people in the 18-34 age group (44.4% in this age group) reported using the internet, 40 people (85.1%) in the 65+ age group did so (35-49 years: 32/62.7%; 50-64 years: 64/72.7%). No correlation could be found between education level, gender or knowledge test score and internet use to search for information. Respondents most frequently searched for sample templates for precautionary documents (138/86.3%) and general information (124/77.5%). Around 1/3 of respondents (62/38.8%) were looking for information or assistance in drafting precautionary documents. The verification of concrete statements (22/13.8%), the search for advisory bodies and persons (17/10.6%) or assistance with concrete examples of use (19/11.9%) were less in the foreground of the search.

Experiences in searching for information

The experiences of the 160 respondents who had already searched for information on precautionary documents on the internet varied considerably. Table 2 shows the percentage of agreement for the items frustration during the search, uneasiness about the quality of the information, comprehensibility of the information as well as satisfaction with the search for the entire sample as well as relevant subgroups.

The older adult group tended to report less frustration, less anxiety about the quality of the information, better comprehension, and greater overall satisfaction with the information search. The frustration experienced correlated significantly weakly negatively with the age of the respondents (p = -.191, p = .016). There were also differences in the understanding of the information found in different age groups (Kruskal-Wallis test: chi-square(3) = .916, p = .001). Adults aged 35 to 49 were significantly less likely to say that they easily understood the information found on precautionary documents than those aged 18 to 34 (z = 3.728, p = .001, effect size r = .498), 50 to 64 (z = -3.051, p = .014, effect size r = .311) and over 65 (z = -2.851, p = .026, effect size r = .336). No significant differences were found for gender or educational level.

Looking at the results of the knowledge test, it is noticeable that these are related to the perceived experience of searching for information on the internet. As the knowledge score increased, people reported less frustration (p = -.258, p = .001), less anxiety about the quality of the information (p = -.263, p < .001), better comprehensibility (p = .334, p < .001) and greater overall satisfaction with the information search (p = .320, p < .001). However, these results do not allow us to draw any conclusions about the causal relationship between knowledge and experience of searching for information on the Internet.

Zustimmung zu den Items der Sucherfahrung im Internet				
	Frustration n (%)	**Beunruhigung Qualität n (%)**	**Verständlichkeit n (%)**	**Zufriedenheit n (%)**
gesamt (n = 160)	72 (45,0%)	71 (44,4%)	82 (51,2%)	81 (50,6%)
Geschlecht				
weiblich	47 (48,5%)	45 (46,4%)	53 (54,6%)	47 (48,5%)
männlich	22 (36,7%)	24 (40,0%)	28 (46,7%)	33 (55,0%)
Altersgruppe				
18–34	13 (54,2%)	11 (45,8%)	17 (70,8%)	12 (50,0%)
35–49	14 (43,7%)	17 (53,1%)	8 (25,0%)	13 (40,6%)
50–64	31 (48,5%)	28 (43,7%)	34 (53,1%)	29 (45,3%)
65+	14 (35,0%)	15 (37,5%)	23 (57,5%)	27 (67,5%)
Bildungsniveau				
niedrig	0 (0%)	1 (50,0%)	2 (100%)	2 (100%)
mittel	52 (48,6%)	46 (43,0%)	49 (45,8%)	52 (48,6%)
hoch	20 (39,2%)	24 (47,1%)	31 (60,8%)	27 (52,9%)

Tab. 2: Agreement with the items of the search experience on the internet.

Discussion

The internet is an important source of information on precautionary documents such as living wills and health care proxies. Consistent with other studies (Schaeffer et al. 2021; Neuert et al. 2017), a large proportion of respondents stated that they use or consider using the internet as a source when searching for information; preference is given to searching on websites of official institutions (such as ministries). What was striking in the present survey was the high number of people over 65 who use online services (around 85%). In comparable representative studies in the field of health information, the values for the older age group of 40.0% (Schaeffer et al. 2021) and 31.8% (Neuert et al. 2017) were significantly lower than the values observed here. One possible explanation for this difference between the over-65s and the

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younger age groups in the present study is the topic of precautionary planning, which becomes more relevant with advancing age, which is also reflected in the increased occurrence of precautionary documents in older age groups (IfD Allensach 2014; Fleischmann et al. in peer review).

If one looks at the reported search experiences (frustration, concern about quality, comprehensibility, general satisfaction), a very heterogeneous picture emerges. The respondents were divided roughly in half between people who reported positive experiences and few difficulties and people who stated the opposite. Unexpectedly, the age group of the over 65s frequently reported positive experiences when searching for information on the internet. This raises the question of whether older people are actually highly competent in dealing with information on the internet or, on the contrary, are too uncritical and overestimating themselves with regard to information search on the internet. Previous studies suggest that older people have greater difficulties in dealing with digital information (Schaeffer et al. 2021). Whether and how perceived and actual search success are related remained mostly open in previous studies. The results of the present study suggest that objective and subjective search success are close to each other. People with more knowledge about precautionary documents reported less frustration, less worry about information quality, better understanding of the information, and greater overall satisfaction with the search. This suggests that people can indeed realistically assess their search success, provided digital information is used as a central source of information. However, due to the study design, no causal relationship can be proven.

The present study makes it clear that a considerable proportion of the older population also accepts information offers on the internet and can also be reached via these channels. Against the background of the varying quality of the digitally available information (Stuart 2017) and the low level of digital health literacy in older age groups, the question arises as to how digital offers can be integrated as profitably as possible into care. On the one hand, the focus must be on the digital offers themselves as well as on the searchers' abilities to correctly evaluate the information found online in order to avoid an additional burden on the care system from poorly or incorrectly informed people. Further research to clarify the connection between the already frequently measured subjective health literacy and objectively measurable competencies appears necessary.

Limitations

The survey is not representative of the German general population due to regional recruitment. A wide age range was reached, but a large part of the respondents, and thus proportionally more than in the general population, had an academic education. The call for participation using the keyword ‚precautionary documents' may also have led to a selection of people with above-average information about the topic, and the online survey may have led to the participation of people with a particularly high digital affinity. In fact, the proportion of people who already have a precautionary document is higher in the sample than would be expected in the general population. Studies with a representative sample are necessary to confirm the results. In addition, it must be noted that due to the study design, only self-assessments of the respondents were collected and biases in the response behaviour cannot be excluded. The present study does not allow any conclusions on causal relationships. <<

Authors' statement

The authors declare that there are no conflicts of interest. The study was carried out as a sub-project of the project ‚Myths about living wills - transfer of professional skills to reduce misconceptions in counselling on advance directives (MyPatH)' funded by the Federal Ministry of Health.

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