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## **Towards e-health literacy on depression for adolescents: Information sought versus information gained**

Cornelia Wolf, Rosanna Planer, Diana Elschner, Lina Funfack, Maximilian Morlock, Paulin Ostrowski, Verena Ribnitzky, Lydia Schwarz, Manuel Tietze, Phoebe Toennessen, Christina Weidl and Pia Weinforth

*Institute for Communication and Media Studies, Leipzig University, Leipzig, Germany*

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Address correspondence to Prof. Cornelia Wolf, Professor for Online Communication, Institute for Communication and Media Studies, Leipzig University, Nikolaistraße 27 – 29, 04109 Leipzig. E-Mail: [cornelia.wolf@uni-leipzig.de](mailto:cornelia.wolf@uni-leipzig.de)

## **Abstract**

Half of all mental health disorders start occurring by the age of 14, with depression being the fourth most common disorder among adolescents worldwide. The prevalence of depression among German adolescents has nearly doubled in recent years. When it comes to mental health information sources, the internet has become a common medium for adolescents. Hence, to raise awareness of depression among this group, their specific expectations for online information and services must be met. Due to a lack of mixed-methods studies, this study therefore compares adolescents' expectations of online information and support services about depression (Study I), and information provided on the internet (Study II). Based on a literature review, qualitative interviews with adolescents were conducted ( $N=34$ ). Moreover, the multi-platform online communication of nine German non-profit organizations (NPOs) that aim to improve information and care for people suffering from depression was analyzed using quantitative content analysis ( $N=1,435$ ). Comparing the information gained from both studies, results indicate that expectations for fact-based communication were met by the NPOs frequently providing information on depression and requested experience reports were often communicated. However, discrepancies are apparent in the use of communication channels and videos, and the particular importance of personalization is evident.

## **Introduction**

Depression is a ubiquitous disorder which is prevalent around the world and a major cause of suicides. Around 322 million people worldwide are affected (World Health Organization, 2017). Half of all mental health disorders start occurring by the age of 14, though most cases initially remain undiagnosed and thus untreated (Kessler et al., 2007; Thapar et al., 2012). Despite this, depression is the fourth most common of all mental health disorders among adolescents (World Health Organization, 2020). Research shows that the prevalence of depression among German adolescents has nearly doubled in recent years – the highest increase of any age group (Steffen et al., 2020). Therefore, educating adolescents about depression is necessary, with many young people unable to recognize a mental health disorder, an essential prerequisite for successful help-seeking (Leighton, 2010; Olsson & Kennedy, 2010). They need to be empowered to recognize and name symptoms, distinguish them from other conditions of distress and be able to seek professional support. This is understood as mental health literacy (MHL) (Jorm, 2012).

Adolescents commonly seek mental health information and services online (Kauer et al., 2014). This means that, in addition to MHL, they must possess e-Health Literacy (EHL) to identify, adequately understand, assess and classify this information (Norman & Skinner, 2006; Okan et al., 2019). To seek and use depression-related online information and services, adolescents' expectations must be met by the information and services available. Due to their charitable and non-commercial purpose, most information and services in Germany are communicated by non-profit organizations (NPOs), whose goal is to contribute to better care for people suffering from depression. Existing research on information-seeking behavior concerning mental health information and services usually refers to specific therapy services, applications or programs (Grist et al., 2017; Van Meter et al., 2019), or investigates the expectations of young people in Anglo-American countries and Australia (Bradford & Rickwood, 2014; Cunningham et al.,

2014; Havas et al., 2011; 2014). Despite the higher prevalence of depression among German adolescents in a global comparison, studies thus far do not examine their expectations when seeking information and help on depression. Furthermore, studies do not match preferences with the information and services actually communicated by NPOs, leading to a lack of mixed-method designs combining both the recipient and organizational perspectives. Such a comparison could help to “provid[e] the types of professional services that young people will use” (Rickwood et al., 2005, p. 25). To match these perspectives and examine whether and how adolescents’ needs regarding online information-seeking on depression are being met, this study first examines how adolescents seek online information about depression (RQ1), before analyzing which information are offered online by non-profit organizations on the topic of depression (RQ2).

## **Literature review: Digital mental health information**

### ***Conceptual framework: help-seeking model and mental (e-)Health literacy***

Help-seeking is the overarching framework identified in the literature (Pretorius et al., 2019). It generally applies to the behavior of actively seeking help from other people, such as understanding, advice, information, treatment and support in response to a problem or stressful experience (Rickwood et al., 2005). Help-seeking is conceptualized in four steps. These are influenced by MHL, which describes the “knowledge and beliefs about mental disorders which aid their recognition, management or prevention” (Jorm, 2012, p. 231) and is a precondition for successful help-seeking. In the help-seeking model, individuals need to be aware of symptoms and able to appraise that their problem may require intervention. They must be able to articulate and express their problem to themselves and others, therefore the individual’s MHL is crucial. Furthermore, sources

must be available and accessible and the help-seeker has to be willing to disclose his inner state to these sources (Pretorius et al., 2019).

As online sources become increasingly relevant, Pretorius et al. (2019) apply the model to the internet. The ability to “seek, find, understand, and appraise health information from electronic resources and apply the knowledge gained to addressing or solving a health problem” can be defined as EHL (Norman & Skinner, 2006, p. 1). Current EHL research focuses on correlations of EHL with individual variables and health information-seeking (Zamir et al., 2019), such as motivational factors and the assessment of online help offers.

A differentiation can be made between formal and informal help-seeking: Formal help-seeking refers to help and support from professionals, whereas informal help-seeking concerns assistance from individual social supports (Pretorius et al., 2019). Young people often seek help from informal sources. Online informal help sources are commonly found on social media sites and often contain personal experiences of individuals (Fergie et al., 2016).

### ***Empirical dimensions: reception perspective***

For adolescents, the internet has become a primary source for information searches about mental health (Birnbaum et al., 2017; Fergie et al., 2016; Park & Kwon, 2018). Websites and platforms of health institutions, government agencies, NPOs, and physicians are most frequently described as sources, thus highlighting the importance of formal help-seeking online. Adolescents often seem to conduct uncoordinated keyword searches (search engines) and select websites based on prioritization in search results lists (Freeman et al., 2018; Gazibara et al., 2020; Havas et al., 2011; Pretorius et al., 2019). Social media platforms like Facebook, Twitter, and YouTube are other relevant sources (Hausmann et al., 2017; Park & Kwon, 2018).

Regarding the assessment of online help offers on mental health, the main concerns for adolescents are the privacy provided by online platforms and the trustworthiness and reliability of information (Cunningham et al., 2014; Pretorius et al., 2019). Trustworthiness, expertise, objectivity, and comprehensibility of information sources are mentioned as important factors in assessing credibility (Cassidy, 2007; Hausmann et al., 2017; Park & Kwon, 2018). Adolescents rate websites as credible based on factors such as regular updates, the provision of verifiable information and eye-catching design. They also assess websites according to their domain name, reputation, and popularity (Hausmann et al., 2017; Park & Kwon, 2018). According to Freeman et al. (2018, p. 9), adolescents prefer structured websites with clear information and “a professional tone, with language that was understandable and age-appropriate.” Overall, adolescents often intuitively assess websites, without having a clear appraisal strategy. Hence, an increased EHL is suggested to decrease the barriers adolescents face in their search for and assessment of online health information (Freeman et al., 2018).

Due to the lack of focus on Germany in existing research, this study asks:

*RQ1: How do adolescents in Germany seek information about depression?*

### ***Empirical dimensions: organizational perspective***

Three main studies examine how to raise awareness for mental health disorders from an organizational perspective. They indicate that the availability of mental health support for adolescents is a major challenge as most interventions occur in educational settings (Aguirre Velasco et al., 2020), that digital ads can help to reach adolescents seeking mental health support (Birnbaum et al., 2017), and note the potential of e-Health communication strategies (Parikh & Huniewicz, 2015).

In this context, research states that “public health communicators need to step further into social media engagement” (Heldman et al., 2013, p. 13). In corporate

communications in general, personalization is considered one of the dominant trends and research shows that attributing content to a specific person (Human Voice) can help build relationships with stakeholders (DiStaso & McCorkindale, 2013). A study on depression in Germany showed that psychiatrists, friends and family, affected persons, and physicians are the four most important sources for people seeking help on depression, again suggesting a high value of Human Voice (Stiftung Deutsche Depressionshilfe, 2020).

In addition, the presentation of content can be differentiated based on journalistic genres (Broersma, 2005). Accordingly, information can be conveyed in a fact-based, narrative or opinion-based manner. Research on strategic communication of NPOs reveals that informational posts evoke less interaction from recipients than engaging content (Gao, 2016).

Social media was mainly researched regarding informal content provided by private users (Fergie et al., 2016; Hausmann et al., 2017). A broader approach could consider professional websites and social media information spread by institutionalized actors. In Germany, NPOs with the purpose of raising awareness of depression are important information providers. To overcome the research gap, this study aims to provide a comprehensive analysis of the information provided by thematically relevant NPOs that conduct educational work on depression in Germany:

*RQ2: What information is provided by non-profit organizations in Germany on the topic of depression?*



## **Mixed-method design: Matching expectations and information provided**

### ***Qualitative interviews***

Since little is known about how young people seek information about depression, this question was addressed using qualitative interviews to elaborate on the subjective perspective of adolescents. Therefore, semi-structured guided interviews were chosen to ensure flexibility, narrow the topics covered and obtain comparable data with a larger sample (Doody & Noonan, 2013). The interview guideline was differentiated into dimensions deducted from the literature review: knowledge, personal touchpoints, help-seeking, information-seeking, preferences and concerns in information offers, credibility, and future perspectives. The dimensions of knowledge and personal touchpoints with depression operationalize the concept of MHL, whereas help-seeking refers to the help-seeking model (Christensen & Griffiths, 2000; Jorm, 2012; Rickwood et al., 2005). The guideline was checked in a pre-test by an expert in educational science and child and youth psychotherapy (DeMaio & Landreth, 2004).

The population was defined as German adolescents aged 14-18. A deductive sampling was carried out using a quota procedure according to gender, age, type of school, and place of residence. In total, 34 interview participants were recruited using snowball sampling via social media and teachers at several German schools (Kristensen & Ravn, 2015, p. 725).

### ***Quantitative content analysis***

To examine what information about depression is provided online, a content analysis was applied (Downe-Wamboldt, 1992).

The population consisted of the online communication content of German NPOs that educate on the topic of depression<sup>1</sup>. A set of online channels were selected: websites, social media platforms, and blogs. The units of analysis differed depending on the type of media channel and were divided into webpages, home pages of forums and blogs, social media profiles, and posts<sup>2</sup> on social media platforms and blogs. As the number of units to be included in the analysis was determined on a channel-specific basis, the selection was based on a combination of mean value from span<sup>3</sup> and a complete analysis. In the end, the sample consisted of 1,435 units of analysis.

Codebook categories examined, for example, the specifics of the different platforms, including a) addressing of recipients (e.g., Human Voice), b) provided information (e.g., depression-related information), c) references and networks (e.g., support services) and d) visual and textual presentation of content (e.g., journalistic genres). A pre-test with a random sample ( $n=660$ ) was conducted by five trained coders, yielding a significant intercoder reliability result with an average of  $\kappa = 0.63$  (Landis & Koch, 1977).

## **Results: interviews reveal little knowledge but clear expectations**

### ***Knowledge***

The respondents' level of knowledge about depression was almost exclusively rated as low. The majority were able to state that depression is a mental illness or at least a

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<sup>1</sup>Aktionsbündnis seelische Gesundheit, Bundesverband der Angehörigen psychisch erkrankter Menschen e.V., Depressionsliga, Eckhard Busch Stiftung, Freunde fürs Leben e.V., Irrsinnig Menschlich e.V., Robert Enke Stiftung, Stiftung Deutsche Depressionshilfe, Stiftung für seelische Gesundheit

<sup>2</sup>Published between January and October 2020

<sup>3</sup>Example calculation (Instagram): Number of Instagram posts  $312-21 = 291 : 6 = 49$  (mean value from span)

negative mental state. *“People with depression are people who are very hidden in our society because it is an illness that you can’t see”*<sup>4</sup> (I1, m, 14). According to their statements, characteristics and symptoms of depression can be divided into internal and external indications. Some of the participants mentioned that it was difficult to recognize if a person had a mental illness. *“If someone is hiding it, [...] you have to go deeper to notice it”* (I4, f, 16).

### ***Information-seeking behavior***

When asked about their search behavior, the majority of respondents reported they did not actively search for information about depression unless they themselves or people in their direct environment suffered from depression. *“I have never sat down at the computer and googled depression [...] but you always come across the topic in articles or on the internet”* (I8, m, 17). Participants mostly encountered the topic through discussions at school or in conversations with friends. When asked specifically about their online search behavior, most reported they usually use Google to look for information about depression, with websites, Wikipedia, and social media channels such as YouTube and Instagram also mentioned as suitable research sources.

### ***Adolescents’ expectations***

Concerning expectations of the content, interviewees indicated that naming symptoms, characteristics, information about depression, and measures for mental health problems is important. In addition, support services in the near vicinity, lived experience reports and scientific contributions were mentioned. Regarding webpages, adolescents preferred

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<sup>4</sup>For a better comprehensibility, the direct quotes from German-speaking respondents have been translated into English.

a simple design and a clear structure with short, understandable multimedia content. *“A simple text would be good, maybe one or two images or a graphic that just clarifies the content”* (I8, m, 16).

In terms of the originators of the information, the study shows that most respondents are more likely to believe real people who have had experience of depression. Reading informational content from psychology professionals and persons with experience of depression in forums or on social media was preferred. *“People who just tell their story ... and report from their everyday life or what happened there and what experiences they had [...] can be very interesting”* (I4, f, 17).

### ***Credibility expectations***

Adolescents' expectations regarding credibility could be determined based on the subfactors comprehensibility, objectivity, expertise, and trustworthiness (Cassidy, 2007; Hausmann et al., 2017; Park & Kwon, 2018; Young et al., 2012). Concerning comprehensibility, online support services should contain few medical terms and limited amounts of text. Some participants explicitly mentioned that visual representations facilitate access to information, and offered additional layout ideas, such as short video clips, graphs, charts, and images with brief explanations. *“You should just break it down and not use so many medical terms so that the information is just packaged compactly, use simple language and maybe underline it [...] by pictorial representations”* (I30, f, 16).

Presented information and facts about depression are perceived to be objective if supported by statistics or studies. *“If it's factual, then definitely not if opinions are in there, but rather reliable statistics and research”* (I11, m, 17). Expertise is attributed to the authors if the information comes directly from or references medical or government institutions, while trustworthiness is perceived when the information directly originates

from psychology professionals. Again, the experiences of people personally affected should be described. *“It would be good to be able to read something about the author or psychologist [...] something personal [...] then you just have a little bit of a feeling of who wrote it [...] and feel like you're being taken care of”* (I3, f, 14).

## **Results: content analysis shows focus on formal information dissemination**

### ***Sources of information and references***

Investigating which information channels are available, results from the analysis of German NPO content show that informal sources of help, such as the social network, are rarely referred to (7%,  $n=1,435$ ). In contrast, formal support services play a relevant role: A weak significant correlation was found between the reference to digital help and advice services and the involvement of health professionals (33 %,  $n=1,435$ ,  $V=.17$ ,  $p<.001$ ) as well as information about psychology professionals (35 %,  $n=1,435$ ,  $V=.22$ ,  $p<.001$ ).

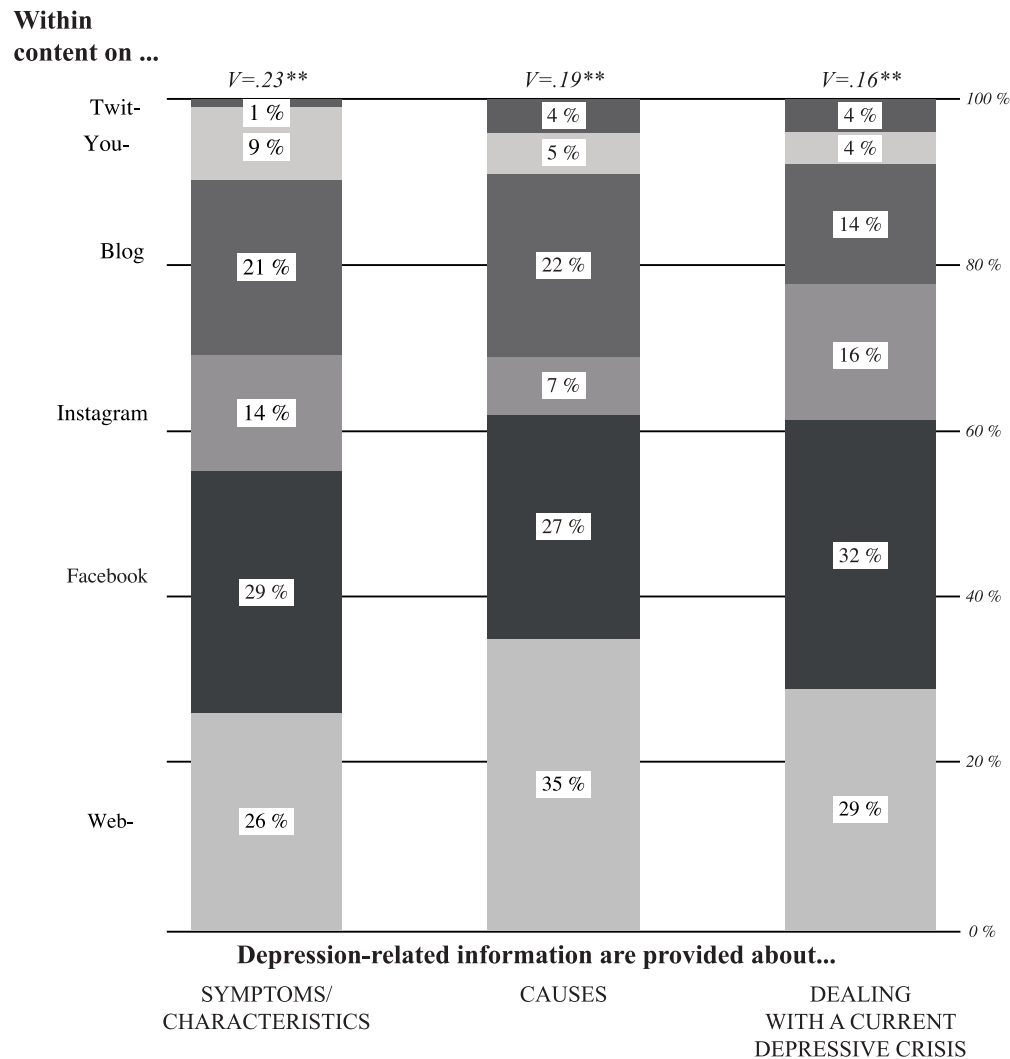
Furthermore, 41 percent of the content analyzed linked to further online content. In particular, reference was made to further websites (56%), either the author's own (26%) or external (22%) sites. Websites were linked especially within the content on Facebook (56%) and YouTube (54%), but less frequently on Instagram (24%). A medium significant correlation could be identified for the reference to websites within individual platforms ( $n=1,435$ ,  $V=.40$ ,  $p<.001$ ).

### ***Provided information***

With specific reference groups rarely addressed, the content was predominantly generic (71%). Affected persons (14%) and relatives (4%) were also seldom explicitly addressed ( $n=1,435$ ).

Expertise, as a factor of credibility, could rarely be identified. Overall, information about psychology professionals was given more frequently (11%) than about physicians and medical institutions (5%,  $n=1,435$ ).

Support centers play a relevant role, especially in providing information to reduce stigma and help relatives and affected people. Information about symptoms and characteristics was given in 14 percent of the cases, and information about causes of depression was provided in eight percent. With regard to dealing with affected relatives, who represent a relevant point of reference, information was given in eleven percent of analyzed units, while every fifth unit provided information on how to deal with a specific crisis. Facebook and websites play a key role in the presentation of this information and there is often a correlation between the platform and the type of information provided (Figure 1).



$n = 1,435$

$**$  : High significance ( $p < .001$ )

$0 \leq V < .1$ : no correlation;  $.1 \leq V < .3$ : low correlation;  $.3 \leq V < .5$ : medium correlation;  $.5 \leq V < .7$ : high correlation;  $.7 \leq V < 1$ : very high correlation

*Figure 1: Depression-related information on online channels.*

### **Presentation of information**

In addition to the information itself, its presentation is a relevant evaluation standard for recipients. This includes the extent to which the content can be attributed to a specific person (Human Voice) and is presented as a lived experience report. Human Voice could often be identified (42%,  $n=1,435$ ), and while people affected were given a voice, this was less often the case for professionals or relatives (Figure 2). 62 percent of the

information about psychology professionals was also presented in conjunction with Human Voice ( $n=607$ ,  $V=.14$ ,  $p<.001$ ), and public figures were presented (43%,  $n=607$ ,  $V=.149$ ,  $p<.001$ ) especially when affected persons were addressed.

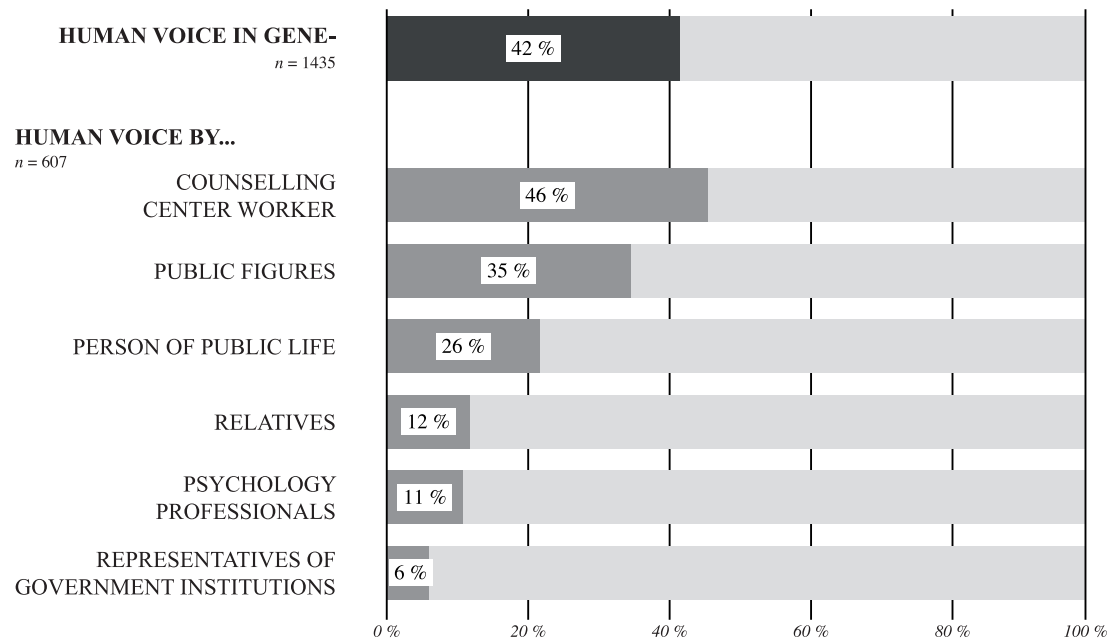


Figure 2: The use of Human Voice as part of information providing.

Moreover, 20 percent of analyzed content units includes an experience report, mostly attributable to one or more specific persons (77%,  $n=1,435$ ,  $V=.10$ ,  $p<.001$ ). People are given a voice concerning information on dealing with a specific crisis (53%,  $n=1,435$ ,  $V=.103$ ,  $p<.001$ ) and dealing with affected relatives (56%,  $n=1,435$ ,  $V=.098$ ,  $p<.001$ ).

Despite the supposedly narrative character of reported experiences, the contents are mainly fact-oriented (54%) and less frequently narrative (40%) or opinion-oriented (6%) ( $n=1,435$ ,  $V=.222$ ,  $p<.001$ ). The same distribution can be identified for information about symptoms and characteristics, which are presented as fact-based even more often (62%,  $n=1,435$ ,  $V=.13$ ,  $p<.001$ ).



Visual elements are common (84%), mostly photos (54%), followed by graphics and illustrations (32%) and mixed forms such as memes (15%). Only ten percent of the cases included videos. Experience reports are more often accompanied by photos than graphics and illustrations ( $n=1197$ ,  $V=.15$ ,  $p<.001$ ).

### **Discussion: Identifying the gap**

Answering RQ1, key findings from the literature indicate that MHL and EHL among adolescents and parents are low, which was confirmed for knowledge about depression by the interviews conducted. Interviewees knew little about specific help and treatment options, even though most of them already had contact with depression. Considering preferred channels of online information, whereas previous studies identified Facebook, Twitter, and YouTube as preferred channels (Hausmann et al., 2017; Park & Kwon, 2018), interviewees here particularly highlight Instagram and YouTube. Organizations, however, primarily disseminate their information on websites, which seem to be a reference point, and Facebook.

Answering RQ2, depression-related information offered by organizations largely coincides with the expectations of the young people. The interviewees' motives, depending on the degree to which they were affected, were searching for opportunities for self-diagnosis, seeking help and information, and reading testimonials. Regarding the importance of formal sources, the study partially validated their significance by references to facilities and psychology professionals. Hence, background information on depression and how to deal with it are frequently provided.

Focusing on the interviewees' need for testimonials, regardless of whether they are unknown or public figures, it can be stated that reported experience and personalization are already an essential part of the information provided by German online support services. Affected persons themselves, often public figures, share their

personal stories mostly by text and photo, while experts such as psychology professionals are very rarely presented.

In contrast to previous studies, interviewees do not confirm the internet as the primary source for help-seeking, preferring instead informal offline sources. The importance of the social environment as information source and help for adolescents, however, is barely taken into account by the analyzed organizations. This might be due to legal reasons, since the accuracy of the information provided there cannot be guaranteed. Furthermore, organizations provide only limited information on how to interact with those affected. Therefore, considering the findings of this study might help institutions to increase MHL and EHL of adolescents, and provide a more targeted outreach. In addition to formal information, organizations should reflect that young people primarily turn to their social environment when seeking help.

### **Limitations and implications**

The generalizability of the interviews is limited by the low representativeness of the sample, which was predominantly female and 16-18 years old. Most interviewees were higher educated and lived in urban areas. Although a representative distribution was sought, it is not essential in qualitative research and might be neglected in favor of sample diversity (Maxwell & Chmiel, 2014). For the content analysis, it must be noted that the results only provide information about the communication of the non-profit organizations studied. Although these represent a relevant part of the information market on depression, other commercial and public organizations also communicate. Future studies could apply a comparative design.

Nevertheless, discrepancies between the information provided by the organizations surveyed and the expectations of the adolescents interviewed offer potential for a more targeted outreach in professional communication about depression to increase

MHL and EHL of adolescents. Greater use of human voice and testimonials, including personalization of health professionals, is one way to meet their interests. The study also indicates the importance of well-maintained websites and a focus on social media, particularly Instagram and YouTube. In addition to formal information, organizations should consider that adolescents primarily turn to their social environment for help. This type of support in dealing with serious crises, as well as offline information services in school settings, for example, should be recognized as important intermediaries to be targeted with information. Organizations should also reach out to adolescents as family and friends of people with depression.

To increase adolescents' awareness of depression, improving their online MHL is critical. Today, getting information is not difficult; rather, young people face the challenge of being able to assess it. Hence, for organizations, the credibility and comprehensibility of their online information, as well as its engaging presentation, are critical to achieving their organizational goals. Adapting to the expectations and help-seeking behavior of young people could increase their use of professional help and reduce the proportion of undiagnosed depression.

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No potential conflict of interest was reported by the authors.

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