Covid-19, the perfect time to broaden our horizons about social media use in oncology? A survey study with healthcare professionals caring for youth with cancer

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Research Article

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Abstract

Purpose

The study aims to explore the attitudes of Swiss healthcare professionals towards the use of social media in adolescent and young adult oncology and to examine whether the ongoing social restrictions due COVID-19 might have altered these attitudes.

Methods

This study was cross-sectional in design. The subjects were healthcare providers working in pediatric or adult oncology settings in Switzerland. We performed descriptive and inferential statistical analyses.

Results

While considered useful, only a small minority of participants actually used social media for professional reasons and considered themselves skillful in using these platforms. Although institutional guidelines were deemed crucial to improve social media use, many respondents seemed unaware of their existence. Only a minority reported an impact of Covid-19 on their attitudes towards the professional implementation of social media.

Conclusion

The global health crisis creates important challenges for young patients with cancer and their healthcare providers. In times of social restrictions, social media may be promising tools to facilitate health information provision, connectivity and patient care. Virtual mentorship and target social media training interventions might be the best way to improve familiarity with social media and with ethical guidelines for their use.

Introduction

Cancer is still the most common disease-related cause of death among adolescent and young adults (AYA) in high-income countries [1]. Despite improved cure rates [2], long-term survival of AYA cancer survivors is significantly worse compared with pediatric and adult patients [3]. The underlying reasons for this disparity are likely to be a combination of medical-biological (e.g. unique cancer types in AYA and their inferior response to treatment) and psycho-social factors (e.g. AYA are developing physically, cognitively and emotionally) [2, 4, 5].

The physical, emotional, existential, and social impact of cancer upon AYA's wellbeing is enormous. Whilst it is increasingly recognized that AYA are a special group, in most countries their needs go unmet

because due to small patient numbers specialized AYA treatment centers are rare or non-existent and pediatric and adult care programs are not used to manage the problems unique to this population [6–8]. The COVID-19 pandemic risks to exacerbate these already existing vulnerabilities as oncology departments worldwide are facing the challenge of balancing the risk of interrupting treatment, follow-up care and screening with the risk of exposing patients to infection [9].

The pandemic is likely to have an adverse effect not only on the physical, but also on the psycho-social wellbeing of cancer patients [10]. According to a recent qualitative survey study in Italy [11], AYA reported being worried to get infected and to suffer from severe complications. These findings are confirmed by the cross-sectional study by Košir and colleagues which shows that 6 in 10 AYA felt more anxious since the COVID-19 outbreak [12]. Their concerns were mostly related to compromised immunity, and the impact of delayed treatment on survivorship. Patient education is crucial to adequately support AYA and to help them cope with this stress. However, only one quarter of the participants declared receiving COVID-19 related information from their healthcare professionals (HCPs) and more than 50% expressed the need for more AYA tailored communication [12].

Research indicates that during the pandemic patients have sought informational and emotional support on social media (SM) and Twitter in particular [13]. This should not come as a surprise: SM platforms are increasingly recognized as promising tools in the delivery of health information and behavioral interventions to the public, especially to AYA with cancer given the extensive use of SM among this age cohort [14, 15]. Likewise, the recent health crisis has motivated oncologists to use SM to exchange information and experiences with colleagues across the globe [16]. Other HCPs have used WhatsApp to respond in a time-effective way to queries from cancer patients [17]. SM networks have also proved to be an important means to engage the public in preventive behaviors against COVID-19 infection [18]. On the other hand, the misinformation circulating on SM related to the pandemic is a serious problem as it constitutes an important threat to public health [19, 20]. Regrettably, SM are also used to advertise unapproved diagnostic tests and false cancer cures and in times of lockdown with the disruption of cancer protocols, patients and families are even more susceptible to these kinds of products [21].

Research before the pandemic shows that despite the potential patient- and HCP-related benefits of SM, HCPs often take a conflicted stand on adopting SM for professional reasons due to lack of time, health-related misinformation on SM, privacy concerns and the desire to maintain a professional relationship with patients [22–24]. A recent (pre-Covid-19) focus-group study with HCPs caring for AYA cancer patients and survivors in Switzerland confirmed these findings [15]. The aim of the present survey study was to explore (a) the attitudes of Swiss HCPs towards SM use in AYA oncology and (b) whether the ongoing social restrictions due to the pandemic might have altered these attitudes.

Methods

Study Design

Using an online survey tool (soscisurvey.de), we distributed a cross-sectional survey to capture Swiss AYA oncology providers' general attitudes towards SM as a support tool in their care for AYAs and to examine a potential impact of the Covid-19 pandemic on their professional SM use. This quantitative part was part of a larger project on the use of SM in AYA oncology which aimed to explore HCPs apparent reticence to make greater use of SM, to explore their perceptions of the barriers to integrate these platforms on an institutional level, and to better understand their view on AYA's cancer-related use of SM. The qualitative results have been reported elsewhere [15].

A clarification of responsibility (jurisdictional inquiry) was submitted to the leading ethics committee (EKNZ, Basel) which stated that the research project falls outside the scope of the Swiss Human Research Act (Art. 2) because data was collected anonymously and health experts were surveyed. The EKNZ stated that the project fulfills the general ethical and scientific standards for research with humans. Furthermore, the online survey tool was approved by the University's data protection office.

Study population and study sample

Since AYA cancer patients are treated either in pediatric or adult oncology settings, we approached oncology providers from both settings. Oncology providers included all occupational groups (e.g. nurses, physicians, psycho-oncologists, or social workers) involved in the care of AYA with cancer in Switzerland. The only inclusion criterion was that participating HCPs were caring for or had cared for AYA patients or survivors. A total of 79 individuals participated in the study and 62 surveys were completed. Accordingly, survey completion rate was 78.5% (62/79). As a result, the N varies across variables. We cannot confidently estimate the number of providers who received the survey and thus survey response rate cannot be calculated. However, the participants came from all three major Swiss language regions (German, French, Italian) and from both pediatric and adult oncology settings.

[Tab.1]

Recruitment and data collection

The data collection period was between July and October 2020. Based on previous collaborations from the qualitative part of the study we used a stratified convenience sampling approach to recruit participants, that is, we explicitly targeted subpopulations within the population of AYA oncology providers (e.g. pediatric and adult oncology providers, different occupational groups, working in all three major Swiss language regions) to capture variation in these key characteristics of the study population.

The study team requested each contact person at the collaborating oncology centers to share the survey among their colleagues and to invite them to fill in the survey. The survey invitation was sent to eight adult centers and seven pediatric ones. Once data collection was completed, data was exported from the online tool and imported into statistical software.

Study survey

The study instrument was developed based on a scoping review of the literature [15] and input from collaborating physicians. Also, focus groups with AYA oncology providers and interviews with individual AYA cancer patients informed the survey tool [15]. The survey captured the following data: (a) demographics and professional background, (b) personal and professional SM use, (c) HCP's assessments of the usefulness of SM for various professional purposes (e.g. networking, engagement with patients, education), (d) possible Covid-19 impact on the professional use of SM, (e) institutional use of SM and guidelines on SM use, and (f) challenges, benefits, and a facilitation of SM use in AYA oncology. The questionnaire consisted of items with categorical responses (e.g. department, language region, SM use), Likert scales (e.g. usefulness of SM), and open items (facilitation of SM use in AYA oncology). The tool was pilot tested by 3 AYA oncology providers in July 2020. Minor adaptations were made which did not change the survey's overall structure and purpose.

Statistical analyses

Statistical analyses were performed using SPSS 26.0 (SPSS Inc., Chicago, IL). First, descriptive analyses were performed. Second, independent factors associated with providers' assessments of the usefulness of SM in AYA oncology were determined using multiple linear regression analysis and differences in these assessments between occupational groups were examined using ANOVA analysis. Statistical significance level was set at $p < .05$. For the multiple linear regression analysis, assumption checks were performed before interpretation of the model.

Results

Providers' demographic characteristics and use of social media

Of the AYA oncology providers, 72% were women, 35% worked in the pediatric oncology setting, 51% in a university hospital, and 44% were nurses, and 40% physicians. Almost all providers used SM for private reasons and on a daily basis. Only half of them used SM professionally and the majority did so only

rarely. It has to be noted that some participants did not answer all items resulting in missing values which, in turn, lead to different sample sizes for some of the variables and analyses respectively. Further demographic and SM use related information are presented in table 1.

Providers' assessments of usefulness of social media

Only a small majority of HCPs (37 out of 66) felt skillful in using SM (56.1% either agreed or strongly agreed, 21.2% either disagreed or strongly disagreed, 22.7% were uncertain). Moreover, providers assessed the usefulness of SM for various professional purposes on a five-point Likert scale (range: 1-5; fig. 1). Overall, they tended towards assessing SM as useful for all five professional purposes (N=66; figure 1): professional life (M=3.6, SD=0.9), educational purposes (M=3.8, SD=0.8), networking (M=4.0, SD=0.7), engagements with patients (M=3.6, SD=0.9), and clinical trial recruitment (M=3.4, SD=1.0).

We evaluated factors associated with providers' usefulness assessments (dependent variable) using multiple linear regression. For this purpose, we calculated a usefulness assessment sum score, composed of the five usefulness assessments. This sum score was reliable (Cronbach's alpha: $\alpha=.812$) and normally distributed (Shapiro-Wilk: $p=.141$, M=18.4, SD=3.2, Mdn=19, Mo=20). Based on a priori theoretical [15] and sample size/predictor ratio considerations [25] we checked the linearity (scatter plots) of the relationships between the dependent variable and the following five predictor variables: providers' skillfulness in using SM (5 point Likert-item: "Do you feel skillful in using social media?"), Covid-19 impact on attitudes towards SM use in AYA oncology (dichotomous item: "Did the COVID-19 emergency have any impact on your attitudes towards the usefulness of social media in your professional life?"), language region (German or Romance), work experience (in years), oncology setting (pediatric or adult). Since the relationship between work experience and the usefulness assessment was not linear, we did not include it in the model. In addition to linearity, the remaining assumptions were checked before interpreting the multiple linear regression model. All assumptions were met: no multicollinearity (VIF and tolerance), independent residuals (Durbin-Watson test), homoscedasticity (plotting the standardized values the model predicts against the standardized residuals obtained), normally distributed residuals (P-P plot), no relevant outliers (Cook's distance). Finally, F-test was conducted to test for the statistical significance of the overall model fit, indicating that the predictors included in the model significantly contributed to the explanation of the usefulness assessment ($F(4, 57) = 5.45$, $p = 0.001$, $R^2=.276$). Adjusted R^2 was 0.226, indicating that 22.6% of variance was explained by the multiple regression model.

Regression analysis revealed that self-assessed skillfulness with social media, the Covid-19 impact on attitudes, and the oncology setting significantly predicted assessment of the usefulness of SM in AYA oncology. In particular, the more skillful a provider was in using SM, the stronger the impact of Covid-19 on attitudes towards SM use in AYA oncology, and the "more pediatric" the oncology setting, the greater was the usefulness assessment (table 2).

[Fig.1]

Finally, analysis of variance between the three occupational groups (nurses, physicians, other) was conducted for the usefulness assessment, revealing that there were no significant effects of occupational groups on the usefulness assessment, $F(2,63) = .363$, $p = .697$.

[Tab.2]

Covid-19 impact on providers' professional social media attitudes and use

Only a minority of AYA oncology providers reported an impact of Covid-19 on their attitudes towards the use of SM in their professional lives (16/64), on the frequency of professional SM use (17/63), on how they use SM professionally (12/64), and on how patients approached providers via SM (4/64). Figure 2 depicts these four variables in more detail. Participants who responded that the frequency of their professional SM use had increased due to Covid-19 were asked to specify the increase in percentages. Out of 17 providers whose professional SM use had increased (27%), 15 specified the respective increase: $M=28.3\%$, $SD=16.0\%$, $Mdn=30\%$, $Mo=30\%$. In open items in which HCPs could elucidate their change in SM attitudes and use, exchange of information and experiences with colleagues and timely responses to patient and family queries were most often cited as important reasons for increased use. One participant tried to combat misinformation: «It happened that on Twitter I argued with some "fake news spreaders"».

[Fig.2]

Institutional use of SM and guidelines on social media use

With respect to the question whether their institution has SM channels ($N=61$), more than a third of AYA oncology providers reported that they did not know (34.4%). More than a third stated that their institution has at least one SM channel (36.1%). In the open comments, Facebook (in 12 out of 18 responses) was most frequently cited as institutional SM platform, followed by Instagram (in 7 out of 18 responses) and Twitter in 5 out of 18 responses). Almost 30 percent (29.5%) of providers reported that their institution has no SM channel.

With respect to the question whether their institution provides guidelines on how to use SM ($N=61$), half of HCPs did not know (50.8%). Almost 30 percent reported that their institution provides guidelines (27.9%) and one fifth stated that their institution does not provide any guidelines (21.3%). Those who

declared that institutional guidelines were in place most often referred to a code of conduct or privacy guidelines but did not report specific SM guidelines.

Challenges, benefits, and facilitation of social media use

HCPs most frequently perceived the following barriers to an implementation of SM in AYA oncology care: legal and ethical issues (43/59), professional boundary violations (27/59), and lack of institutional account and of time (each 22/59). Moreover, the most frequently perceived benefits of implementation of SM were: professional networking (35/58), staying up to date (31/58), patient education (29/58).

In answer to open items, improved training and education of medical staff and clear ethical guidelines were most frequently cited to facilitate the implementation of SM. Two HCPs reported the need for more funding. Two other participants suggested to experiment with telemedicine once or twice per week or to have a specific HCP who is an expert in that field. In the same vein, one provider reported that it requires dedicated professionals as doctors are no communication experts.

[Fig.3]

Discussion

Recently, doctor A. Chiang, founding member of the Association for Healthcare Social Media (AHSM), declared that «Social media is not only a great way to distribute health knowledge, it is absolutely imperative in 2020». Still, as Richard Horton, editor-in-chief of the Lancet, has pointed out, that does not mean that we do not need to be careful about the misinformation that circulates [20]. Much more can and should be done to counter the spread of false information and HCPs and healthcare institutions in particular can take a more active role in this process. This may explain why, over the last decade, cancer associations and medical centers worldwide have encouraged HCPs to actively integrate SM in their clinical practice and why this call has become even stronger with the outbreak of COVID-19. A recent (pre-pandemic) exploratory study in Switzerland indicates that HCPs caring for AYA with cancer are rather hesitant about stepping into the SM arena because they consider it an unsafe professional space [15]. The present survey study aimed to complement these results by examining a potential impact of Covid-19 on HCPs views and professional SM use.

The results show that although HCPs working within the Swiss AYA oncology setting tend to consider SM to be useful for clinical practice, they rarely *actually* use these networks for professional reasons. This paradox elicits different possible explanations. First, research shows that HCPs who make use of SM for work-related purposes are generally between 24 and 34 years old [22, 23, 26], whereas the mean age of our participants was 42, an age cohort which might have less familiarity and thus more difficulty in

adopting new technologies. Indeed, only a small majority of respondents considered themselves to be skillful in using SM. Secondly, in line with other studies [15, 22–24], HCPs expressed concern about patient privacy, violations of professional boundaries and lack of time. These fears might further accrue providers' uncertainty about how to implement SM in AYA care. Third, although clear ethical guidelines were cited as an important means to improve the use of SM, like for the FG study [15], many respondents admitted to being "ignorant" about the existence of SM guidelines on an institutional level and one third was unaware of their hospital's presence on SM. These findings are quite worrisome and might explain why HCPs continue to find it difficult to navigate the SM landscape. Our results are also surprising given that The Swiss Medical Association [27] and various hospitals in Switzerland have developed recommendations on safe SM use.

In the United States, 66% of oncologists answered positively to the Twitter poll question "Has social media helped you navigate the #coronavirus pandemic more successfully?" [16]. In our survey, only a minority of HCPs reported that the COVID-19 pandemic has positively impacted their usefulness assessment and professional use of SM. In other words, although before the health crisis, the majority of HCPs considered SM to be useful for clinical practice, for most of them the pandemic did not result in allocating an increased importance to SM; nor did it lead to an increased use. Moreover, especially the group of respondents that described itself to be social media-savvy reported a more positive view of SM. Like in the USA [16], connectivity with the oncology community seems to have been one of the main drivers to use SM. Our survey findings can have different explanations. First, those who are unfamiliar with using SM networks in their professional lives, are unlikely to do so in a situation of acute stress such as the one caused by the pandemic. Second, as research indicates [28], cultural differences might have an important impact on SM perceptions and behavior: EU users appear to be more hesitant to participate in online communication compared to users in the USA. Moreover, in a small and well-connected country like Switzerland with limited geographical distances, personal contacts with other providers, even during the current health crisis, are quite regular. Third, we should not forget that physicians are generally not at ease with using SM for direct patient care [29] and that this might have not altered immediately with the COVID-19 outbreak. This might be a source of concern if we consider that the pandemic is likely to exacerbate the already existing vulnerabilities of AYA for whom SM are an important means to convey health information.

Our findings suggest feasible ways to improve the implementation of SM in AYA oncology. One of the major obstacles to successful seems to be HCPs modest awareness of existing guidelines which might help them to navigate these networks in a safe and confident way. More efforts should be made by healthcare institutions not only to disseminate guidelines among care providers, but also to make them applicable to the oncology context. A possible way of doing this is that hospitals promote virtual mentorship: to "use" SM savvy care providers as "role models" for a responsible use of SM. In fact, our findings showed that the more skillful a provider was in using SM the higher was their usefulness assessment of SM. This means that they can exert leverage on others to participate in SM educational interventions. It is crucial, however, that both guidelines and SM training are targeted in content and

format towards HCPs. This means that they should provide practical guidance on how to use social media rather than focus on theoretical restrictions and be time-flexible.

Limitations

Stratified convenience sampling might have resulted in an overrepresentation of HCPs with an interest in or a strong opinion on the topic. However, this possible bias does not invalidate our study. In contrast, it renders its findings even more remarkable because this means that even among those HCPs who are interested in SM, professional use remains comparatively low. Also, since we cannot estimate the response rate, we cannot determine whether our sample is representative of Swiss AYA oncology providers. However, Switzerland is a small country with only 9 pediatric (among which 5 university centers) and 15 adult oncology centers (among which 5 university centers). Moreover, since AYA represent only a small fraction of the overall cancer population, the number of Swiss AYA oncology providers is small which means that the responders are likely to present a significant portion of professionals caring for AYA. We captured data from all three major language regions, from both the adult and pediatric setting, and from all occupational groups. Finally, analysis could not be adjusted for clustering within oncology centers (i.e. multiple HCPs per center), since we did not obtain data on oncology centers due to anonymity of data collection.

Conclusion

In time of global health crisis, SM platforms may be promising tools to facilitate health information provision, connectivity and patient care. Our study shows that although many Swiss oncology providers consider SM to be useful when caring for AYA, only a minority actually implements them in practice. Modest familiarity with SM use and existing guidelines might be at the root of this apparent discrepancy. Virtual mentorship and target SM training interventions might be the best way forward.

Declarations

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Conflicts of interest/Competing interests: The authors declare no conflict of interest

Availability of data and material: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Code availability: N/A

Authors' contributions: All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Eva De Clercq, and Michael Rost. The first

draft of the manuscript was written by Eva De Clercq and Michael Rost and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics approval: A clarification of responsibility (jurisdictional inquiry) was submitted to the leading ethics committee (EKNZ, Basel) which stated that the research project falls outside the scope of the Swiss Human Research Act (Art. 2) because data was collected anonymously and health experts were surveyed. The EKNZ stated that the project fulfills the general ethical and scientific standards for research with humans. Furthermore, the online survey tool was approved by the University's data protection office.

Consent to participate: N/A

Consent for publication: N/A

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Tables

Table 1. Demographics and social media use

Demographics	
Age (N=70)	M=42.8 (SD=9.9), Mdn=42.5, Mo=39, Min=26, Max=65
Gender (N=72)	72.2% woman, 27.8% man
Institution (N=72)	51.4% university hospital
Language region (N=71)	35.2% German, 14.1% French, 50.7% Italian
Department (N=72)	65.3% adult oncology
Occupational group (N=72)	44.4% nurse, 40.3% physician, 15.3% other ²
Professional experience ¹ (N=72)	M=16.4 (SD=10.5), Mdn=15.0, Mo ³ =10, Min=0, Max=49
Private and professional social media use	
Private ⁴ : which (N=67)	1.5% none, 97.0% WhatsApp, 50.7% Facebook, 37.3% IG, 32.8% YouTube, 19.4% LinkedIn, 14.9% Twitter, 6.0% TikTok
Private: how often (N=67)	89.6% daily, 7.5% weekly, 3.0% rarely
Professional ⁴ : which (N=66)	50.0% none, 24.2% LinkedIn, 19.7% WhatsApp, 9.1% Facebook, 4.5% Twitter
Professional: how often (N=61)	14.8% daily, 18.0% weekly, 11.5% monthly, 55.7% rarely
Professional: reasons ⁴ (N=67)	27.0% none, 42.9% education, 41.3 networking, 23.8% exchange with colleagues, 9.5% dissemination research, 9.5% patient education

¹in years; ²consisted of psycho-oncologists, psychiatrists, social workers, study coordinators, technicians, admin; ³multiple modes: 10 and 20, smallest is presented; ⁴multiple choice item, and thus percentages can add up to more than 100%.

Table 2. Regression analysis – coefficients

	Unstandardized		Standardized	Collinearity			
	coefficients		Coefficients			Statistics	
	B	Std. Error	Beta	t	Sig.	Tolerance	VIF
(Constant)	20.296	2.169		9.357	.000		
Setting ¹	-2.347	.887	-.348	-2.645	.011	.735	1.360
Language ²	.884	.879	.132	1.005	.319	.735	1.361
Covid-Impact ³	-2.118	.738	-.336	-2.869	.006	.926	1.079
Skillfulness ⁴	1.223	.354	.395	3.458	.001	.975	1.026

Dependent variable: usefulness assessment; ¹dichotomous variable: pediatric vs. adult; ²dichotomous variable: German vs. Romance (French and Italian); ³Dichotomous variable: Covid-19 impact vs. no Covid-19 impact on attitudes towards SM use; ⁴5-point Likert item, ranging from strongly disagree to strongly agree (“Do you feel skillful in using SM?”).

Figures

Figure 1

Providers' usefulness assessments

Figure 2

Impact of Covid-19

Figure 3

Challenges and benefits of SM use in AYA oncology