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Benefit of a palliative care drug information service and user experience: a cross-sectional study using a web-based online survey

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A specialized drug information service can assist professionals in collating relevant information and hereby help to increase medication safety. It is only helpful if the information provided can also be put into practice, though. The aim of this study was to evaluate the benefits of a specialized palliative care drug information service AMInfoPall and its users' experience. A web-based survey among health care professionals subsequent to inquiry between 07/2017 and 06/2018 was conducted. Twenty questions related to the use and transfer of received information into clinical practice and the result of the consecutive treatment. Invitations to participate/reminders were sent out 8 and 11 days after receiving the requested information. The survey's response rate was 119/176 (68%). Most participants were physicians (54%), followed by pharmacists (34%) and nurses (10%), 33/119 (28%) worked in palliative home care teams, 29 (24%) on palliative care units, and 27 (23%) in retail pharmacies. 86/99 respondents had conducted an unsatisfiable literature search before contacting AMInfoPall. 113/119 (95%) were satisfied with the provided answer. Information was transferred into clinical practice as recommended in 65/119 (55%) cases and led to a change in patient status in 33%, mostly improvement. No change was reported in 31% and in 36% it was unclear. AMInfoPall was well accepted and mostly used by physicians and palliative home care services. It provided helpful support for decision-making. The obtained information was mostly well transferable into practice.

1. Introduction

Pharmacotherapy is an integral part of palliative care symptom control. To avoid unnecessarily putting the patient at risk by drug therapy, it is necessary to carefully weigh up different therapeutic options. This can often be challenging due to insufficient data and the complexity of the patient situation (Nationale Akademie der Wissenschaften Leopoldina 2015). Moreover, everyday clinical practice often does not allow to carry out an appropriate patient-specific risk-benefit assessment for each therapy on the basis of current literature and by considering available alternatives; furthermore palliative care clinicians search medical databases such as PubMed ineffectively (Hagemann et al. 2019a, Damarell et al 2016). Access to independent drug information is essential to provide safe and effective medical care and drug therapy of palliative care patients in their specific clinical situation and care setting (International Pharmaceutical Federation 2017; World Health Organization 2002). To meet this need, a free of charge drug information service (AMInfoPall) for health care professionals in German-speaking countries has been established (Hermann et al. 2021). This service provides answers to all questions regarding palliative care pharmacotherapy. The service aims to support professionals in decision-making and thus help to make drug therapy for palliative patients safer and more effective. Queries can either be posed by phone or e-mail. They are answered on weekdays by a pharmacists specialized in palliative care after researching the current literature and databases. The identified scientific evidence is extracted, evaluated, interpreted, and transferred to answer the respective request. The results are routinely reviewed and discussed with a second pharmacist. Only questions regarding palliative care pharmacotherapy are answered. Other questions or those posed by lay people are referred to other information resources. Questions and written answers are routinely recorded in a drug information database (Bundesverband Deutscher Krankenhausapotheker 2019).

The AMInfoPall drug information pharmacists are an integral part of the clinical team of the Department of Palliative Medicine at Munich University Hospital with its own palliative care unit and thus have the necessary practical experience. This clinical knowledge is of great relevance for answering questions on palliative care pharmacotherapy due to the limited scientific evidence in this area and the limited transferability of available scientific data to the individual patient situation (Hagemann et al. 2019a, b; Leitlinienprogramm Onkologie 2019).

For optimal benefit of the service, the provided information should a) answer the question asked, b) be transferable into practice in the case of patient-specific questions and should c) ideally lead to an improvement of the underlying problem/symptom. These benefits for clinical practice in terms of practicability and effects on the patient has not yet been investigated.

Therefore, the aim of this study was to evaluate the benefit and user experience of the inquirers of the AMInfoPall drug information service.

2. Investigations and results

2.1. Study design and development of the questionnaire

A cross-sectional study was carried out using a web-based online survey among users of the Palliative Care Drug Information Service AMInfoPall. The questionnaire (see appendix 1) was developed for the purpose of this study and based on a literature search, questions from similar surveys (Bertsche et al. 2007; Fathelrahman et al. 2008), and consultations of pharmacists, physicians and nurses. The content of the questionnaire was divided into four parts: (1) evaluation of the response received, (2) information on the user's literature research prior to contacting AMInfoPall, (3) demographic data of the participant. In a fourth part, specific questions were asked about the off-label use of drugs. However,

this fourth part was only activated if the query was substantially about off-label use. This part of the questionnaire will be reported elsewhere.

The study population consisted of health care professionals who contacted AMInfoPall with an inquiry related to drugs or drug therapy between 01.07.2017 and 30.06.2018. The online survey tool LimeSurvey was used for programming, hosting and conducting the survey.

2.2. Characteristics of the study population

From 07/2017 to 06/2018, 216 queries reached AMInfoPall. For 175 of these enquiries, an invitation to participate in the survey was sent to the user. For the remaining 41, no invitation was sent because the question was only answered verbally and no written answer was sent. This was the case with very short, simple questions, e.g. the available packaging sizes of a drug. The information about queries was saved in the drug information database only for documentation purposes for AMInfoPall staff (see Fig. 1).

Fig. 1: Study flow from the enquiry to AMInfoPall to the participation in the survey.

119/175 questionnaires (68.0%) were completed and included in the analysis. Incomplete questionnaires were not saved by the survey software and therefore cannot be reported. More than half of the participants were physicians (54%) followed by pharmacists (34%) and nurses (10%). The majority (71%) had an additional qualification in palliative care. A little more than half (67/56%) of the participants worked in the home care sector, the remaining in hospitals (see Table 1).

Table 1: Background of survey participants

	n	%
Gender		
female/male	56/17	77%/23%
Profession		
Physician	64	54%
Pharmacist	41	34%
Nurse	12	10%
Other	2	1%
Worksetting		
Palliative Home Care Team	33	28%
Palliative Care Unit	29	24%
Retail Pharmacy	27	23%
Hospital Pharmacy	14	12%
Hospital (not palliative care unit)	9	8%
Doctor's surgery	5	4%
Palliative Care Counselling Service	2	2%
Hospice	0	0%
Nursing Home	0	0%
Additional qualification in palliative care		
Yes	85	71%
No	34	29%

2.3. Practical relevance and feasibility of the answer received from AMInfoPall

The majority of the users (n=113/119; 95%,) indicated that the information and recommendation received from AMInfoPall fully answered their question. Two participants (2%) stated to have hoped for other information, for one participant (1%) the answer missed the question, and three (3%) participants stated "other" without further explanation in free text. In order to maintain the anonymity of the participants, it was not possible to evaluate the responses according to profession.

Regarding the question "Was the recommendation from the response put into practice?" 55% answered that they had implemented the information and recommendations as suggested, 12% had only partially implemented the response. The response and recommendation from AMInfoPall was not implemented by 24 participants (20%), partly because the patient's situation had changed, the recommendation was impractical to be implemented, or the recommendation from the response did not target the desired outcome. The option "other" was selected by 14% of the participants (see Table 2).

Table 2: Practical relevance and feasibility of the answer received

Was your question answered by the information provided? (n=119)		
Yes	113	95%
No, I was expecting something else	2	2%
No, the answer misses the question	1	0%
Other	3	0%
Has the recommendation from the response been put into practice? (n=119)		
Yes, as recommended	65	55%
Yes, but only partly	14	12%
No, the situation has changed	19	16%
No, recommendations were not applicable	4	3%
No, the recommendation was not aiming at the desired result	1	1%
Other	16	13%
Did the implementation of the recommendation result in a change in the status of the patient? (n=95)		
Yes	31	33%
No	29	31%
Unclear	34	36%
No answer	1	1%

As a result of the realisation of the AMInfoPall recommendation, 33% (n=31/95) of the survey participants reported a change in patient status, 31% (n=29/95) stated that they had not observed any change in the patient. Another 36% (n=34/95) were unsure whether there was an effect from implementing the recommendation, e.g. due to a general deterioration of the patient attributable to a progress of the underlying disease. Among those who indicated a change in the patient status, the effect was reported to be positive in 97% (n=30/31) (Fig. 2).

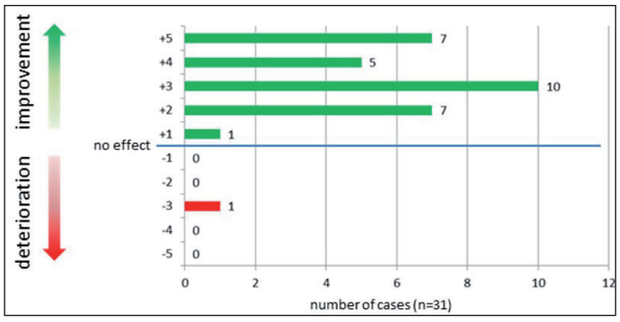

Fig. 2: Effect of transferred information on patients' status on a numerical rating scale. Numbers displayed at the end of the bars indicate the number of responses per bar.

2.4. Information retrieval behaviour of the participants

99/119 participants (83%) had conducted a search for information on their question before contacting AmInfoPall. Twenty respondents contacted AMInfoPall directly without a prior search, the reasons were diverse (see Fig. 3); the high time requirement for searching for information was selected most frequently. The other reasons mentioned were not specified by the participants.

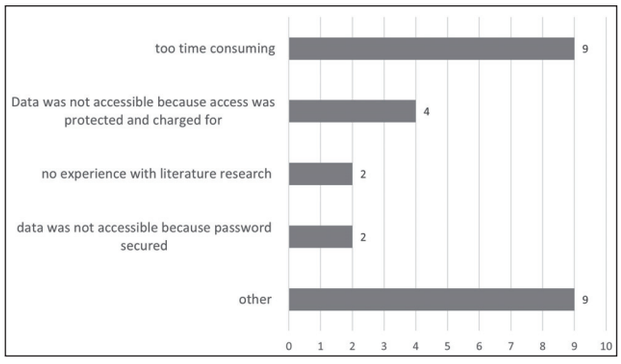

Fig. 3: Frequency of reasons for a direct enquiry to drug information service without prior research. Multiple answers possible.

Of the participants who stopped seeking for information, 87% (n=86/99) did so because they were not able to find a satisfactory answer. Other reasons were, for instance, the high effort of time and the lack of access to the required data (see Fig. 4).

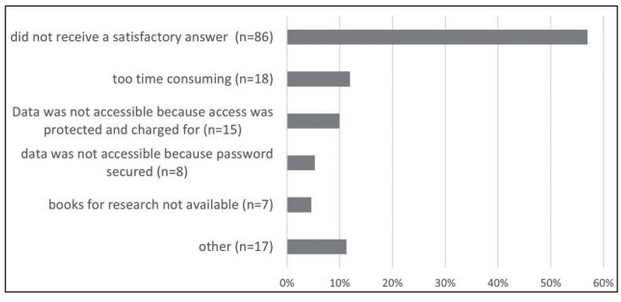

Fig. 4: Reasons for stopping own research (99 respondents; multiple answers possible).

When the participants had already sought information prior to contacting the drug information service, databases were used most frequently (26%; n=55), followed by specialist information from drug manufacturers (25%; n=53), articles from scientific journals 19% (n=41) and books 19% (n=41), as well as other sources not specified by the participants (11%; n=24).

2.5. Satisfaction with the response

Among the respondents, 99% (n=118/119) were satisfied with AMInfoPall's response and recommendation and would make a request to AMInfoPall again in the future.

3. Discussion

A palliative care drug information service supports professionals in challenging therapeutical decisions by providing evidence-based patient-specific information. In our study, we demonstrated that the information provided by the service can be successfully transferred into clinical practice, has a positive impact on the patient's status, and is perceived to be practical and useful by the enquirers. The drug information service frees professionals from searching for information on certain therapeutic questions themselves as they usually don't have the time and resources such as access to certain databased. Therefore, they often have to compromise on decisions based on the best of their knowledge.

The usefulness of different types of drug information services has already been reported (Bertsche et al. 2007; Rutter et al. 2015; Kim et al. 2020; Kusch et al. 2018). In general, regular service evaluations are useful as a quality assurance measure, continuous improvement and further development to meet the information needs and to increase drug therapy safety (Obitz 2011 Strobach et al. 2020, 2021). Key is that the information received is applicable in everyday clinical practice (American Society of Health-System Pharmacists 1996). To the best of our knowledge, however, no assessment of specialised palliative care drug information service has been carried out to date. This is of particular importance as a palliative care drug information service, unlike other such services, requires recommendations to be developed by extrapolating scientific data in combination with the services staff's own experience of clinical practicability. Due to the particular challenges – a lot of off-label use with little scientific basis, little time for trying different treatment attempts and often a home care setting – the feasibility of implementation in practice again plays a special role.

3.1. Feasibility and satisfaction

In line with international recommendations, we assessed the positive impact on drug-related patient care, the improvement of drug use and user satisfaction (Ghaibi et al. 2015). Overall satisfaction with the service was very high even if the recommended intervention could not be implemented because the initial situation had changed or the suggested intervention was rejected by the patient. The respondents indicated that they would nevertheless contact AMinfoPall again in a similar situation. These findings correspond to experiences in other studies, most of which with a focus on user satisfaction (Bertsche et al. 2007; Fathelrahman et al. 2008; McEntee et al. 2010; Rutter et al. 2019). Bertsche et al. for example made a similar observation in a survey on the satisfaction of users of a general national drug information system and the possible positive outcome in terms of patient safety. Melnyk and colleagues also described high user satisfaction of their drug information service and reported that 54.1% of health professionals felt that the drug information benefited the patient, even though the intervention was not used or implemented (Melnyk et al. 2000).
Whether a recommendation is accepted and implemented depends on several factors, which cannot all be influenced by drug information (Melnyk et al. 2000). In our sample, a considerable number of participants indicated that it was not possible to assess a change in the patient's health status after applying the recommendation. In clinical practice, it is often not possible to determine the success or failure of a recommendation after being put into practice as the patient may no longer be cared for (Bertsche et al. 2007). In our study, this was the case, for example, when a retail pharmacist asked for a formulation for the nasal or rectal administration of a drug prescribed by a physician from a home care team. In this case, the pharmacist was able to use the recommendation by compounding the nasal spray, but due to the lack of contact with the patient using it, no information on symptom relief was available. Thus, the situation could not be assessed, even though the patient may have experienced better symptom control and a potential improvement of the situation. The feasibility of recommendations to pharmacists in the outpatient sector is much harder to assess as they may not have direct patient contact which has also been recognised in other studies (Bertsche et al. 2007; Melnyk et al. 2000). However, repeated enquiries by doctors to these pharmacies or repeated enquiries by the corresponding pharmacies to the drug information service can be seen as a surrogate for a response that is perceived as helpful.
The implementation of the recommendations predominantly led to an improvement in the patient status in the cases reported in our survey. This once again underlines the practicability and the practice-oriented response to enquiries.

3.2. Information retrieval

Most of the enquirers had tried to resolve their problems in advance. The proportion in our study was somewhat higher than in other

reports (Hedegaard and Damkier 2009). However, a direct comparison of prior problem solving before contacting the drug information service without considering other factors such as infrastructural conditions, occupational groups and available sources is not appropriate. Well-established standards and sound scientific evidence are scarce in palliative care. Palliative care practitioners may therefore be more familiar with how to search for information and know the available databases. In contrast to another study (Hedegaard and Damkier 2009), participants in our survey consulted databases and specialist information on the relevant drug, but they did not consult colleagues, at least not as relevant information resource. Our study indicates that enquirers lacked everyday professional exchange as a source of information. This is remarkable because there are regular meetings, e.g. in the form of quality circles. Enquirers potentially filter questions where they don't expect sufficient answers in peer discussions. Lack of time resources in and limited access to information were the main reasons why professionals stopped their search for information, as reported in earlier studies (Davies 2007). Physicians also reported limited access to literature as a barrier to their own search for information as access was often subject to a fee and licences for databases were not available for financial reasons (Davies 2007). A drug information service can close this gap by having access to relevant databases and by providing literature and information that has already been evaluated and adapted to the patient's individual situation.

3.3. Strengthes and weaknesses

A strength of our study is a high participation rate through several e-mail reminders. The spectrum of respondents of this survey matches that of the usual enquirers to the AmInfoPall (Hermann et al. 2021). There is some risk of attrition bias, as enquirers who may have been very dissatisfied may also not have wanted to take the time to complete the survey. Yet, it can be assumed that there were also other factors that led to non-participation in the survey, e.g. lack of time. In combination with the good response rate, we can therefore assume that the results were not influenced to any relevant extent. Due to the retrospective nature of the survey without a validated assessment tool, the evaluation of the impact on the patient is limited. In the context of the objectives of this study, this type of assessment can be considered acceptable.

3.4. Further research

The aim of a palliative care drug information service is to support palliative care professionals in their treatment decisions by providing appropriate, patient-specific information on evidence-based treatment options. This should not only optimise the patients' symptom control but also promote drug therapy safety. Our results show that it is possible to meet these targets. Nevertheless, future efforts need to focus on reaching more professionals – not only those who contact the service with an enquiry.

4. Experimental

This study was conducted in accordance with the declaration of Helsinki. Ethical approval for this study was granted by the Ethics Committee of the Ludwig-Maximilians-Universität Munich (17-641UE). The reporting of this survey complies with the CHERRIES criteria for reporting results of internet e-surveys (Eysenbach 2004). The questionnaire consisted of twenty mandatory questions. Predefined, selectable answer options were used as mandatory questions with single choice or multiple choice or "if-then" programming. The first part of the questionnaire aimed to assess the feasibility of transferring the response received into clinical practice, as well as the impact on the patient's status after the recommendation was adopted. In addition, the extent of this impact should be indicated on a scale from -5 to +5, excluding zero. Zero was excluded because the effect could only be rated if the participant had previously indicated that AMInfoPalls' recommendation had been applied and a change had occurred. Furthermore, the participants could indicate how often they had already contacted the service and whether they would do so again in the future. In the second part, prior activities of the enquirers to find knowledge on their query were determined and they were asked whether they had conducted an own literature search, whether they found suitable literature, how they accessed suitable literature and why they still requested support from AMInfoPall. The third part of the questionnaire aimed to obtain more detailed information on the background of the participants, demographic data such as profession, training in palliative care, palliative care experience and area of work. The estimated time needed to complete the online survey was 10-15 minutes. When answering an inquiry to AMInfoPall, health care professionals who contacted AMInfoPall with an inquiry related to drugs or drug therapy between 01.07.2017 and 30.06.2018 were sent general information on the survey and asked for consent to send them an invitation to the survey. In case of consent users were invited to the survey eight days after they received the answer from AMInfoPal. The invitation comprised information about the survey, data protection, and an individual link to the online questionnaire (LimeSurvey). In case of non-response a reminder email was sent after three days, and again after two weeks. The online survey tool LimeSurvey was used for programming, hosting and conducting the survey. Participation was voluntary. No incentives were offered. The online link for anonymous participation was sent in an email to the potential participants as an invitation with information on data protection by generating an individual link for one-time use. Reminders were sent out automatically by the program to ensure anonymity. Patient-related data were not collected. The standard definitions of the American Association for Public Opinion Research (AAPOR), Version 2015 (Research AAFPO 2016) were used to report the response, cooperation and refusal rate. For the evaluation of the free text fields we marked keywords and summarized them manually. For analysis the data entered by the participants was exported from the online survey tool LimeSurvey to Windows Excel® 2012. Descriptive statistics (frequencies, mean ± standard deviation, minimum and maximum) were calculated using Excel. Only complete (i.e. all mandatory questions answered) questionnaires were included in the evaluation. Due to the if-then programming of some questions, the denominator in the number of answers changes.

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References

American Society of Health-System Pharmacists (1996) ASHP guidelines on the Provision Of Medication Information by Pharmacists. Am J Health Syst Pharm 53: 1843–1845.

Bertsche T, Hämmerlein A, Schulz M (2007) German national drug information service: user satisfaction and potential positive patient outcomes. Pharm World Sci 29: 167–172.

Bundesverband Deutscher Krankenhausapotheker e.V. ADKA Arzneimittel-Info-Datenbank. 2019 [available from www.adka-aminfo.de]

Damarell RA, Tieman JJ (2016) Searching PubMed for a broad subject area: how effective are palliative care clinicians in finding the evidence in their field? Health Info Libr J 33: 49–60.

Davies K (2007) The information-seeking behaviour of doctors: a review of the evidence. Health Info Libr 24: 78–94.

Eysenbach G (2004) Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES). Medical Internet Res 6: e34.

Fathelrahman AI, Awang R, Bashir AA Taha IAM, Ibrahim HM (2008) User satisfaction with services provided by a drug information center in Sudan. Pharm World Sci 30: 759–763.

Ghaibi S, Ipema H, Gabay M (2015) ASHP Guidelines on the pharmacist's role in providing drug information. Am J Health Syst Pharm 72: 573–577.

Hagemann V, Bausewein C, Rémi C (2019a) Off-label-prescriptions in daily clinical practice – a cross-sectional national survey of palliative medicine physicians. Prog Palliat Care 1–6.

Hagemann V, Bausewein C, Rémi C (2019b) Drug use beyond the licence in palliative care: a systematic review and narrative synthesis. Palliat Med 33: 650–662.

Hedegaard U, Damkier P (2019) Problem-oriented drug information: physicians' expectations and impact on clinical practice. Eur J Clin Pharmacol 65: 515–522.

Hermann A, Bausewein C, Rémi C (2021) Drug information needs of health care professionals in palliative care: a retrospective evaluation of a palliative care drug information service. J Pain Symptom Manage 62: e28–e37.

International Pharmaceutical Federation (FIP). Medicines information: Strategic development. The Hague: International Pharmaceutcial Federation; 2017. [available from: https://www.fip.org/files/fip/publications/2017-01-Medicines-information-strategic-development.pdf; accessed 30.11.2022]

Kim J, Hoover R, Perkins S, Advani A (2020) Development of a drug information service collaborative in academia. Ann Pharmacother 54: 287–289.

Kusch M, Haefeli WE, Seidling HM (2018) How to meet patients; individual needs for drug information – a scoping review. Patient Prefere Adherence 12: 2339–2355.

Leitlinienprogramm Onkologie. Erweiterte S3-Leitlinie Palliativmedizin für Patienten mit einer nicht-heilbaren Krebserkrankung. Langversion 2.0–August 2019 AWMF-Registernummer: 128/001-OL, [available from: https://www.leitlinienprogramm-onkologie.de/fileadmin/user_upload/Downloads/Leitlinien/Palliativmedizin/Version_2/LL_Palliativmedizin_2.0_Langversion.pdf; accessed 30.11.2022].

LimeSurvey. The online survey tool. https://www.limesurvey.org/de

McEntee JE, Henderson SL, Rutter PM, Rutter J, Davis HJ (2010). Utility and value of a medicines information service provided by pharmacists: a survey of health professionals. Int J Pharm Pract 18: 353–361.

Melnyk PS, Shevchuk YM, Remillard AJ (2000) Impact of the dial access drug information service on patient outcome. Ann Pharmacother 34: 585–592.

Nationale Akademie der Wissenschaften Leopoldina und Union der deutschen Akademien der Wissenschaften. Palliativversorgung in Deutschland – Perspektiven für Praxis und Forschung. 1 ed. 2015.

Obitz P (2011) Dokumentation der Arzneimittelinformation. Krankenhauspharmazie 32: 57–59.

Research AAFPO. Standard Definitions Final Dispositions of Case Codes and Outcome Rates for Surveys 2016 [available from https://www.aapor.org/AAPOR_Main/media/publications/Standard-Definitions20169theditionfinal.pdf; accessed 12.16.2021]

Rutter J, Fitzpatrick R, Rutter P (2015) What effect does medicine advice provided by UK Medicines Information pharmacists have on prescriber practice and patient care: a qualitative primary care study. J Eval Clin Pract 21: 307–312.

Rutter J, Rutter P (2019). Impact of pharmacy medicine information service advice on clinician and patient outcomes: an overview. Health Info Libr J 36:299–317.

Strobach D, Blassmann U, Gundl S, Krebs, Langebrake C, Querbach C, Schuhmacher C (2020) 3. Ringversuch Arzneimittelinformation der ADKA. Krankenhauspharmazie 41: 187–191.

Strobach D, Blassmann U, Klausner S, Krebs, Langebrake C, Querbach C, Schuhmacher C (2021) 4. Ringversuch Arzneimittelinformation der ADKA. Krankenhauspharmazie 42: 57–58.

World Health Organization. Promoting rational use of medicines: core components. 2002. Geneva: World Health Organization. [available from: https://apps.who.int/iris/bitstream/handle/10665/67438/WHO_EDM_2002.3.pdf ; accessed 30.11.2022]