Patients' views on information about medications – a pharmacy-based survey focusing on their information sources and experiences of pharmacists using a clinical decision support system

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The aim of this study was to describe patients' views on information regarding their medication with focus on their experiences with community pharmacists' use of the clinical decision support system EES (electronic expert support system). This study was performed as a survey among patients who were collecting prescription medication at seven Swedish community pharmacies, with 281 respondents (response rate of 68%). Results show that patients receive information regarding their medication from many different sources, with differences related to age and gender. In general, most patients seemed satisfied with the information they had about their medicines, and with the information they got from pharmacists. The study also show that knowledge about how pharmacists work to improve medication safety and how they use EES is low. However, results indicate that many patients have high trust in pharmacists, expect them to check for potential drug related problems and are positive to pharmacists using EES more.

Keywords

clinical decision support system, community pharmacy, information sources, medication information

1. Introduction

Medication is an essential part of health care, and appropriate treatments with medications can cure and prevent many conditions [1]. However, drug-related problems (DRPs) are frequent and cause suffering for patients and lead to substantial costs for society [2-4]. Information or knowledge regarding medications is ever growing and needs to be continuously updated and implemented for decision making for all the involved actors [5-7]. What is more important is that information systems and work procedures support continuity across the different settings. Other than the physician, who has the primary responsibility of assuring that prescribed medications are safe and appropriate, important actors are pharmacists dispensing medication and the patients using the medication. It is important that patients are well informed, understand which medicines they are supposed to take and how to use them, and understand the expected benefits and possible side effects of the drugs [8-11]. The Five Rights is a commonly mentioned approach to reduce medication errors. It can be used as a framework for information requirements in medication management; taking the right drug, at the right time, in the right dose, by the right route, for the right patient [12-14]. Today, patients are becoming increasingly engaged in their own health care, a development that is supported by the growth of information technology in our society [15,16]. Informed, motivated patients' are more likely to value and maintain relationships with healthcare providers, to comply with treatment, and to take an active role in their own health care [17-19]. Research about patients experience of communicating with pharmacists have shown that time is important for trust and satisfaction [20].

Previous research has also studied patients' information sources regarding their medications [21-24]. Online sources are becoming increasingly important for health information [16,25,26]. Information from sources available online varies in quality and reliability, and requires the patient to know how to find the information. Previous research has also shown that some people are unsure of how to find correct,

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reliable information about their medications [27]. In Sweden, 1177 is a service provided by the Swedish health care regions with quality assured advice regarding diseases, care and treatments. Individuals can either visit 1177.se online or call the number 1177 for advice. In Sweden, the patient information leaflets for medications are always included in the medication package and available online via www.fass.se for all registered drugs (provided by LIF, a professional association representing research-based pharmaceutical companies in Sweden). Patients' individual needs for drug information vary, but certain topics are requested more often, both online and in information hotlines, such as information about adverse drug reactions (ADRs) and information about drug-drug interactions (DDIs) [12].

At pharmacies, pharmacists are responsible for safe dispensing of prescription drugs, and to examine prescriptions before dispensing. They are often the last health care provider the patient encounters before using (or not using) a medication. Thus, pharmacists play an important role in detecting prescription errors and preventing DRPs [28-30]. Clinical decision support systems (CDSSs) in the medication management process are being used to reduce the incidence of DRPs, and to improve health care quality and efficiency [5,31-37]. One way of supporting pharmacists in detecting potentially inappropriate prescriptions or avoiding dispensing errors is to use CDSSs [34,38-40]. At pharmacies in Sweden, a CDSS called EES (Electronic Expert Support) is available. EES analyses patients´ electronically stored prescriptions in the Swedish national prescription repository in order to detect potential DRPs such as drug-drug interactions, high doses, therapy duplications, and inappropriate drugs and doses for elderly or paediatric patients. EES has been available in pharmacies since 2010, the level of use was initially low. At the time of the study EES was used for approximately 10% of individuals having their prescriptions dispensed at Swedish pharmacies [41]. The alerts are visible to the pharmacists when they make an active choice to perform an EES analysis. At the time of the present study pharmacists were required to receive a specific consent from the patient to perform an analysis with EES, even though the pharmacist automatically have access to all prescriptions when dispensing prescription medications. After saving the consent for EES analysis, it is valid for future analyses. Previous studies among pharmacists found that one of the things pharmacists found most problematic when using EES, was the need to obtain informed consent in order to perform EES analysis. The time with each patient was not enough to both explain the system, perform the analysis and solve drug related issues [41,42]. Pharmacists wanted to either remove the need for a specific consent or for patients to have more knowledge regarding EES so that it would be easier and less time consuming to receive informed consent.

The aim of this study was to describe Swedish patients' views on information regarding their medication, with focus on their experiences and knowledge with community pharmacists using a CDSS. More specifically, the study aimed to answer four questions:

1. How do patients receive information regarding medications and how do they experience this information?
2. Are there any differences in answers related to age or gender?
3. How do patients experience pharmacist's role in improving medication safety?
4. What are patients' knowledge and experiences regarding the CDSS EES used by pharmacists?

2. Method

This study was performed as a survey among patients who were collecting prescription medication at Swedish community pharmacies. Data was collected using a paper based questionnaire at 7 different community pharmacies in Sweden. The pharmacies were located in Luleå, Kalmar, Grängesberg, Värnamo and Torsås and belonged to three different pharmacy chains. Data was collected by five students doing their degree project for a bachelor degree in pharmacy (Pharmacist programme Linnaeus University). Data was collected during approximately 100 hours in total during two weeks (March 12-25th 2018). Data collection was conducted at different hours and different days to collect responses from different types of patients. Individuals visiting the pharmacies during data collection to get prescription medication dispensed was asked to take part in the study. They were informed of the study and if they agreed to participate they filled out the questionnaire and returned it at the pharmacy. Those that were asked but did not agree to participate in the study were regarded as non-respondents to calculate response rate. Criteria for inclusion were all adult individuals collecting prescription medication during the time of data collection. Criteria for exclusion were individuals not understanding Swedish enough, or not having cognitive ability to read, understand and answer the questionnaire. In

total 412 patients were asked to take part in the study, from those 281 agreed and 133 declined. A total of 50 individuals were not asked to participate due to the exclusion criteria. The questionnaire was paper based and comprised 10 questions divided onto 3 pages. It was developed by one of the researchers together with the students for the purpose of the study. The questions focused on respondents practical experiences, were based on previous research methodology and findings, and as such, were not developed from any theoretical framework. The questions included multiple-choice questions, statements where the respondents gave their degree of agreement according to a six-point Likert scale (where 1 represents "do not agree at all" and 6 represents "totally agree"), and open-ended questions that could be answered in free text. Together with the questionnaire the patients were given one page with information about the study, how data would be handled and analysed, as well as contact information to the main researcher (also supervisor for the students). Before the questions about EES, the questionnaire had a short text explaining EES ("*EES is a computer based support to help the pharmacist identify any potential DRPs, for example several similar medications, medications that could interact or medications inappropriate because of age or doses that are too high*").

Data collected by all students at the different community pharmacies were registered and merged into one data set in Excel. The complete data set was used by the students to answer different questions for their individual degree projects. In the current paper, new analysis based on the complete data was carried out. IBM SPSS Statistics 26 was used to analyse the answers. To analyse differences related to age or gender, Chi-squared test for independence was used. P-values <0.05 was regarded as statistically significant. In the Chi^2 tests, the Likert scales were dichotomized into a binary scale where 1-3 represented "do not agree" and 4-6 represented "agree". The open-ended questions were analysed by manifest content analysis, where text-based replies where reviewed based on common themes expressed in their manifest content.

Before the study, an application for ethical advice was submitted to the Ethical Advisory Board in South East Sweden. Based on the Ethical Advisory opinion (EPK 476-2018, date 07-03-2018) some small adjustments in methodology and information to study participants were made before the start of the study. No individual data besides the answers to the questionnaire was collected. Before the study the managers of the community pharmacies gave their written permission for conducting the study at their pharmacies.

3. Results

The questionnaire had a response rate of 68% (281/412). The respondents had a mean age of 54 years, 52% were female and 92% had Swedish as native language (Table 1). More than 90% of the respondents agreed with the statements "I feel safe with my medication treatment" (n=254), "It is easy to know which medications I should use and when" (n=260) and "I receive the information I need regarding my medications" (n=259) (Figure 1). The median answer for all those statements was 6 on the 6-point Likert scale.

Table 1 Background information of respondents (n = 281).

Background characteristics		**n**	**%**
Gender	Female	147	52.3
	Male	134	47.7
Age	<20	10	3,6
	20-29	19	6,8
	30-39	31	11,0
	40-49	40	14,2
	50-59	56	19,9
	60-69	57	20,3
	70-79	50	17,8
	80-89	13	4,6
	>=90	1	0,4
	Missing answer	4	1,4
Native language	Swedish	259	92,2
	Other	20	7,1
	Missing answer	2	0,7

		Answers on Likert scale	"Agree"	"Do not know"	Missing answers
1	I feel safe with my medication treatment	269	254	0	12
2	It is easy to keep track of which medications I should use and when	272	260	0	9
3	I receive the information I need regarding my medications	268	259	0	13

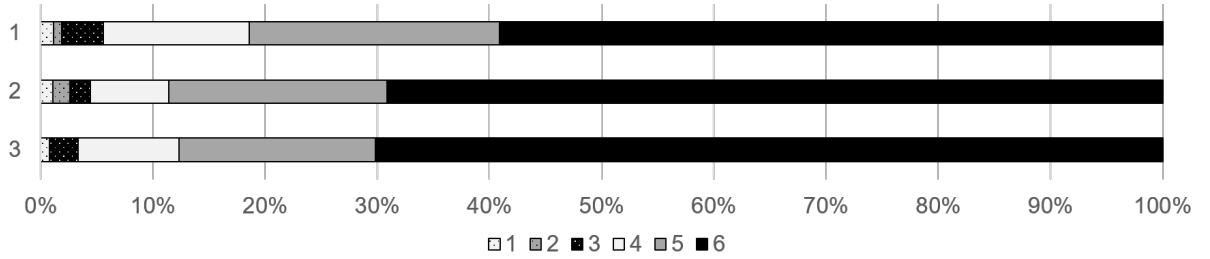

Figure 1 Respondents degree of agreement with four statements regarding their medications. The proportion of answers on the Likert scale is shown in the bar chart where 1 represents "do not agree at all" and 6 represents "totally agree". For each statement the number of answers on the 6 point Likert scale is given, together with the number of answers with "Do not know" and number of missing answers.

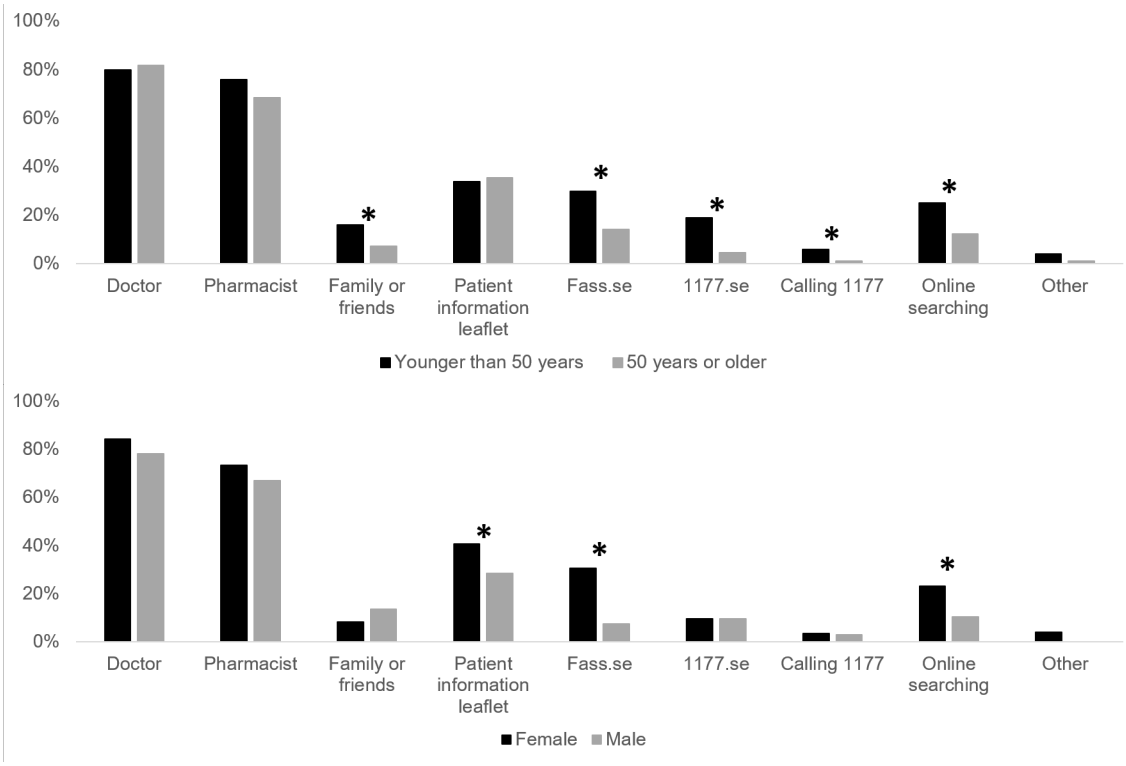

Figure 2 How the respondents receive information and advice regarding medications. (A) Comparison between respondents younger than 50 years (n=100, 36%) and respondents 50 years and older (n=177, 64%), (B) comparison between females (n=147, 52%) and males (n=134, 48%). Significant differences are indicated with * ($p<0.05$, Chi-squared test).

The respondents' answers showed that doctors and pharmacists were the most common sources of information and advice regarding medications. There were significant differences ($p<0.05$) in information sources related to age and gender. Respondents younger than 50 years more frequently used family and friends, the online sources fass.se, 1177.se and called 1177 for advice, as well as searched for information online compared to respondents aged 50 years or older (Figure 2). Female respondents more frequently used the patient information leaflet, fass.se, and searched for information online regarding their medications, compared with male respondents (Figure 2). Answers to the statements regarding pharmacists, revealed that the majority of respondents expressed a high trust in pharmacists by agreeing to a high degree that pharmacists made sure that their treatment is safe, appropriate and safe to combine (Figure 3).

		Answers on Likert scale	"Agree"	"Do not know"	Missing answers
1	The pharmacist makes sure my treatment is safe	224	217	44	13
2	The pharmacist makes sure my treatment is appropriate for me	200	182	69	12
3	The pharmacist makes sure my medications are safe to combine	198	181	69	14
4	The pharmacist gives me the information I need to use my medications	252	244	19	10
5	The advice I get from the pharmacist has the same quality no matter when and where I collect my medications	211	187	56	14

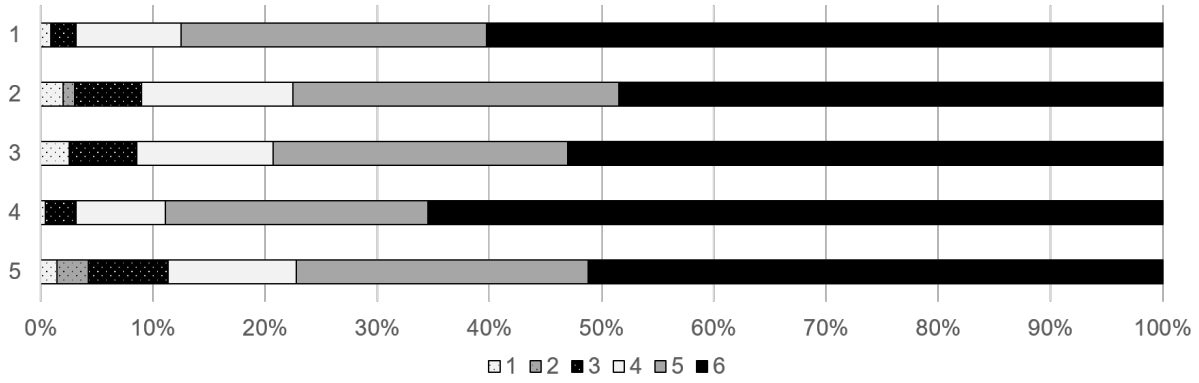

Figure 3 Respondents degree of agreement with five statements regarding pharmacists. The proportion of answers on the Likert scale is shown in the bar chart where 1 represents "do not agree" at all and 6 represents "totally agree". For each statement the number of answers on the 6 point Likert scale is given, together with the number of answers with "Do not know" and number of missing answers.

Few respondents (19%) knew about EES, 26% of all respondents said they had given their consent to pharmacists performing EES analyses and 13% said they knew that the pharmacist had performed an EES analysis (Table 2). For the first statement about EES "It is clear to me when the pharmacist is using EES" the median response was 4 and approximately 63% (n=50) of those that answered on the six-point Likert scale agreed with the statement. This statement also had significant differences related to age ($p<0.05$). Among the respondents younger than 50 years 47% agreed with the statement, compared with 76% among respondents aged 50 or older among those older than 50. For all other statements in the questionnaire (Figure 1, 3 and 4) there were no significant differences related to age, gender or language. For the last statement regarding EES "I would like the pharmacists to use EES every time I collect medication" 88% (n=96) of those who answered on the Likert scale agreed with the statement. For all of the statements regarding EES the majority of respondents answered "do not know". Although the last statement had more replies than the other three (Figure 4).

The respondents also replied in free text to the questions about additional need for support or information, and if they feel safe/confident with their medication. Most of the respondents replied that they did not lack any information and many seemed satisfied with the information they had and the support they got from pharmacists. They also expressed that they could ask pharmacists for more information when they needed, and felt comfortable and safe with the service they got. Many described having positive encounters and expressed trust in pharmacists. A few of the comments included suggested improvements, such as more information about side effects; the wish to avoid generic substitution as it is hard for the elderly when medications look different; and that physicians could explain in a better way and present alternatives. Many respondents commented that they did not have previous knowledge about EES, or that they heard about this system for the first time during this study. Others stated that EES was not applicable for them since they did not take multiple medicines or bought for someone else. Some expressed that they took it for granted that pharmacists had the knowledge they needed for safe dispensing, or that they hoped that they would use EES.

Table 2 Respondents answers regarding knowledge and experience with pharmacists using EES (n = 281).

Question	Answer (multiple choice)	n	%
Did you know about EES (before the information in this questionnaire)?	Yes	53	18.9
	No	201	71,5
	Do not know	21	7.5
	Missing answers	6	2,1
If you know about EES, how did you learn or get information about it?	From pharmacist at pharmacy	73	26,0
	From brochure	23	8,2
	From pensioner organisation	3	1,1
	Do not know	72	25,6
	Other	13	4.6
Have you given consent for EES to be used to analyse your medications?	Yes	74	26,3
	No	99	35,2
	Do not know	88	31,3
	Missing answers	20	7,1
Do you know if pharmacists at a pharmacy have used EES to analyse your own, or a family member's, medications?	Yes	35	12,5
	No	76	27,0
	Do not know	160	57.0
	Missing answers	10	3,6

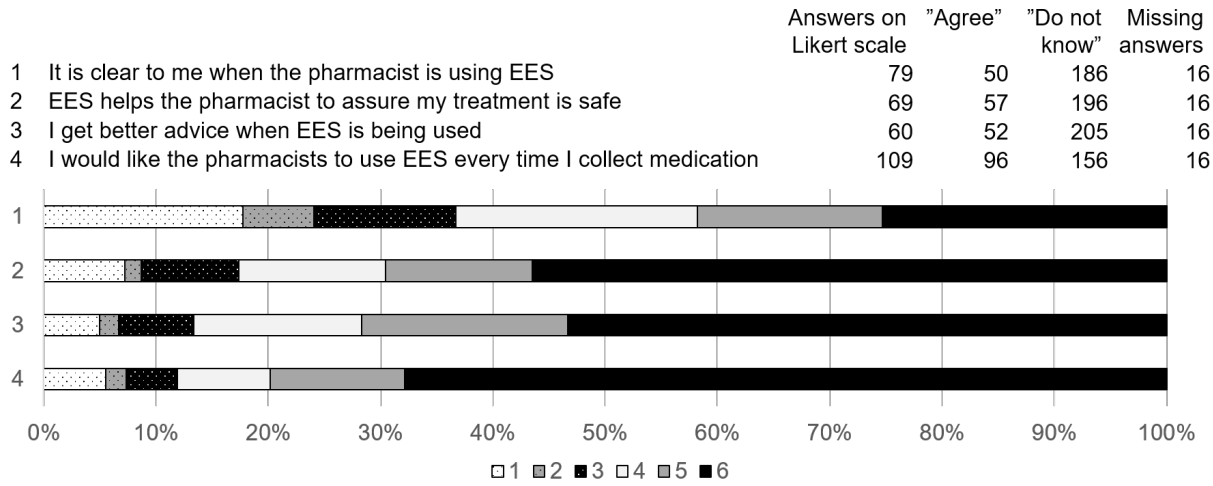

Figure 4 Respondents degree of agreement with four statements regarding EES. The proportion of answers on the Likert scale is shown in the bar chart where 1 represents "do not agree" at all and 6 represents "totally agree". For each statement the number of answers on the 6 point Likert scale is given together with the number of answers with "Do not know" and number of missing answers. The number of respondents in total was 281.

4. Discussion

The respondents in this survey used various sources to find more information about medicines. Doctors and pharmacists where the most common sources. A number of significant differences where seen by age and gender in the use of other information sources. In general, many patients seemed satisfied with the information they had about their medicines, and with the information they got from pharmacists. In the comments as well as the level of agreement on statements, they expressed a high trust in pharmacists and felt safe with their treatment. Most of the respondents did not know about EES before this study. On the question if they wanted EES to be used, most of those who replied were positive. The younger respondents used online sources of information to a higher extent. Both age and gender differences are in line with findings of previous studies [27]. Although information from doctors and pharmacists were most common, younger adults used additional information sources (internet searches, web based health resources, call services, and family and friends) more than the older participants in this study. This is in line with previous research conducted in Sweden [43]. Older adults seems to be slightly more passive in acquiring additional health information, or they prefer to ask family and friends.

A majority of respondents expressed a high trust in pharmacists making sure that their treatment is safe, appropriate and different medications safe to combine. This highlights the importance that this profession needs to have both time to identify and solve any drug-related problems and easy access to CDSSs to fulfill the trust that patients put on them. It is also worth to note that few of these patients had experienced that their pharmacists used EES while dispensing medicines. Hence, patients might believe that pharmacists already access this type of information, and trust that they by default are ensuring that their medications are safe to combine. This supports the idea of making it easier for pharmacists to conduct analyses in EES. The low knowledge about EES indicate that patients may need more knowledge and awareness about pharmacists work to improve medication safety, and the opportunities to use EES to ensure a safe medication use. This is particularly important for those using multiple medicines. Previous research has also reported that information about DDIs is among the most requested by patients searching drug-related information [12]. However, for pharmacists to be able to use EES, they need time to conduct the analysis and thus discuss the result with the patient. Research about patients experience of communicating with pharmacists, have shown that time availability is important for trust, satisfaction and cooperation. What is more, patients with a higher risk of DDIs tend to have higher trust in their pharmacists [20]. Removing unnecessary steps in this process, such as the need for a specific informed consent for the EES analysis, may provide the pharmacists with more time to focus on the issues that matter for medication safety.

In previous studies [41,42], obtaining consent was also the step that pharmacists found most problematic, thus the limited time frame. From an ethical perspective, some might interpret removing informed consent as an action that violates privacy or contradicts the idea of shared decision making. However, a number of issues speak in benefit of this removal. Firstly, the analysis per se does not involve privacy issues, as pharmacists already have access to the list of prescriptions medicines a particular patient have when they are dispensing prescriptions. Conducting an EES analysis does not provide the pharmacist with any new information about the patient. Secondly, providing patients with information about a system and asking them to make a choice, may be both stressful and cognitively demanding. The time is restrained and patients may not understand how the system works or what they are consenting to. Thirdly, more information and unnecessary choices may deviate patients' focus from more important information, such as information about how to safely use their medicines. This is particularly important to consider for elderly when dispensing their medicines. More choices and higher age have a negative effect on decision making, why it is often recommended to reduce the number of unnecessary choices for elderly navigating in complex health systems [44,45]. Fourthly, the empirical results showing patients high trust in pharmacists and the belief that they ensure a safe medication use, imply that patients already expect that their pharmacists have access to the information needed to fulfil this trust. In health care, physicians use similar CDSS without having to get consent or explaining it to the patient beforehand. Instead, they can focus on solving any potential problems and discussing the specific issue with the patient. Some time after this study, the eHealth Agency has reassessed the legal requirement for consent regarding EES analysis and concluded that it was not necessary from alegal point of view, and since June 2020 it is no longer required that the pharmacist receives a consent specifically for the EES analysis.

The methodology in this study has several strengths and limitations. The strengths include that data was collected at several pharmacies and at different times during the day. It also includes control of the response rate. There are also several limitations with the study. First, data collection was not possible to randomize and collection at pharmacies are known to miss certain demographics, such such as the very old who often have help with collecting medications [46]. Also, our criteria for exclusion contribute to our results not being generalizable to all groups. The questions used have not been not validated in other studies. There were missing answers to some questions, and for the questions about EES the majority answered with "I do not know". Also, there were some inconsistencies in the answers to the questions related to EES; there were fewer respondents that answered yes to the question "Did you know about EES?" than answered the next question "If you know about EES, how did you learn or get information about it?". The reason for this in unclear but we chose to include all answers in the analysis anyway. To be included in the study, it was not required that the patients had multiple medications. The missing answers may be partly explained by respondents only having one or few medications, thus not finding the questions relevant for them. The positive attitude towards pharmacists seen in our study might have been affected by the study's setting.

Future research should study effects of the removal of consent for EES analysis, as well as clinical effects of pharmacists using EES. Future research should also further study how to provide information and support about medications to different groups of patients in order not to exclude for example elderly. Also, the use of information sources by different demographics, e.g those who are

not native Swedish speakers should be further studied. What is more, most of the respondents replied that doctors and pharmacists are the main source of information about medicines. This result may be affected by the study's setting, or the sampling criteria focusing on those getting prescriptions. Future research could investigate whether other information sources are more important for information about over the counter drugs.

5. Conclusions

Patients receive information regarding their medication from many different sources where doctors and pharmacists are the most common. There are differences in how patients receive information related to age and gender. Results indicate a high trust in pharmacists and their ability of making sure their medication is safe. Most patients think that they have the information they need about their medications. The knowledge and awareness about pharmacists using the decision support EES at pharmacies when dispensing medication is very low which indicates that it is difficult for pharmacists to receive an informed consent. However, our results also show that many patients are positive to pharmacists using EES more and that some may already expect pharmacists to control for potential DRPs.

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