

**The use of an eHealth application to assess symptom burden as a  
basis for symptom management in hospice care,  
a mixed-method feasibility study**

Name:	Sanneke Heij (4289617)
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Master course Clinical Health Sciences, Nursing Science, Utrecht University.	
Supervisor:	Everlien de Graaf
Name teacher:	Irina Poslawsky
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## ABSTRACT

**Background:** Patient reported outcomes are the gold standard to assess symptom intensity of hospice patients. The Utrecht Symptom Diary application (USD-app) is an eHealth self-assessment tool to measure symptom intensity.

**Research Question:** Is the eHealth USD-app, which assesses hospice patients' symptom intensity, feasible as a basis for symptom management in daily hospice care?

**Method:** This sequential, explanatory mixed-method feasibility study was performed from February to June 2017. The study parameters were; demand of the USD-app for hospice patients, acceptability of the USD-app for hospice nurses and integration of the outcomes of the USD-app in symptom management in daily hospice care. Data were collected using 1) a self- designed questionnaire and 2) focus groups. Data analysis were performed using descriptive statistics and content analysis respectively.

**Results:** 80/151 nurses were enrolled. On average the app was used for 332/413 patients, mostly with help from a nurse. Overall 63% of nurses were satisfied with the USD-app. The use of the app supported deploying appropriate interventions and improved insight into the course of symptoms and the patients' well-being. Nurses specifically found the introduction of the app and the evaluation of interventions difficult.

**Conclusion:** Overall the USD-app is feasible indicated by a demand of over 70% of hospice patients using the USD-app and high acceptability by nurses. Nevertheless some improvements were suggested since the USD-app not fully integrated in to daily care. Knowledge, competences, the nurses being aware and changing their gatekeeper attitude and support from the multiprofessional team are key for a successful adoption.

**Recommendations:** The implementation of the USD-app should be imbedded in the implementations of symptom management. Nurses should learn the competences associated with eHealth. Using additional scales in the USD-app should be explored in future research.

**Key words:** Symptom management; Patient Reported Outcome Measurement[MESH]; Palliative Care[MESH]; Hospice Care[MESH]; Telemedicine[MESH].

## SAMENVATTING

**Achtergrond:** Patiënt gemeten uitkomsten zijn de gouden standaard om symptomen te inventariseren bij hospice patiënten. De Utrecht Symptoom Dagboek applicatie (USD-app) is een eHealth patiënt-gerapporteerd meetinstrument om symptoomlast te meten.

**Onderzoeksvraag:** Is het gebruik van een eHealth applicatie, om symptoom last in kaart te brengen, bruikbaar als basis voor symptoom management in hospice zorg?

**Methode:** Deze sequentiële, verklarende, gemengde-methode haalbaarheidsstudie werd uitgevoerd van februari tot juni 2017. Studieparameters waren het gebruik van de USD-app door hospicepatiënten, de acceptatie van de USD-app door hospiceverpleegkundigen en de integratie van de uitkomsten van de USD-app in symptoommanagement in dagelijkse hospicezorg. Data werd verzameld door 1) een zelf gemaakte vragenlijst en 2) focusgroepen. De analyse is gedaan met beschrijvende statistiek en kwalitatieve inhoudsanalyse.

**Resultaten:** 80/151 verpleegkundigen hebben meegedaan. Gemiddeld werd de app gebruikt voor 332/413 patiënten, meestal met hulp van verpleegkundigen. In totaal waren 63% van de verpleegkundigen tevreden over de USD-app. Het gebruik van de app helpt bij het inzetten van de juiste interventies en inzicht krijgen in het verloop van symptomen en het welzijn van de patiënten. Verpleegkundigen vonden specifiek de introductie van de app en de evaluatie van interventies moeilijk.

**Conclusie:** Over het algemeen is de USD-app haalbaar, door het gebruik van de USD-app voor meer dan 70% van de patiënten en de hoge acceptatie door verpleegkundigen. Niettemin werden enkele verbeteringen voorgesteld aangezien de USD-app niet volledig in de dagelijkse zorg is geïntegreerd. Kennis, competenties, bewustwording van verpleegkundigen over hun invulgedrag voor patiënten en dit veranderen, en ondersteuning van het multiprofessionele team zijn de sleutel voor succesvolle adoptie.

**Aanbevelingen:** De implementatie van de USD-app moet ingebed worden in de implementatie van symptoommanagement. Verpleegkundigen moeten competenties met betrekking tot eHealth leren. Het gebruik van andere schalen in de USD-app moet verder worden onderzocht.

**Zoekwoorden:** Symptoommanagement; Patiënt-gerapporteerde uitkomstmeting; Palliatieve zorg; Hospice zorg; eHealth.

## INTRODUCTION

Each year, according to the World Health Organization (WHO), 40 million people need palliative care<sup>1</sup>. The WHO defines palliative care as “an approach that improves quality of life of patients and their families facing the problem associated with life-threatening illness, through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”<sup>2</sup>. This indicates that early identification and assessment of symptoms in palliative care is important.

In the Netherlands, specialised palliative care is provided in hospices. There are two types of hospices: volunteer-driven hospices, which provide hospice care by trained volunteers supported by healthcare providers, and professional-driven hospices with specialised nurses, physicians and other care providers. Patients with a life expectancy of >3 months have access to hospice care.

The majority of hospice patients in professional-driven hospices suffer from a mean of six to seven symptoms concurrently<sup>3</sup>. According to palliative reasoning, symptom management consists of assessment, intervention, monitoring and evaluation<sup>4</sup>. Routine, comprehensive symptom assessment enables palliation of the wide range of symptoms that may affect quality of life of hospice patients<sup>5</sup>. To assess and monitor symptom intensity, the gold standard is patient-reported outcomes (PROs)<sup>6</sup>. The Edmonton Symptom Assessment System (ESAS), a clinical tool to assess symptom intensity, is widely used in, and validated for, palliative care<sup>7-9</sup>. A Dutch-adapted translation of the ESAS is the Utrecht Symptom Diary (USD).

Over the years, the USD was used in a paper version. Nowadays, there are several barriers for using the paper version of the USD<sup>10,11</sup>. A study concluded that due to time limitations, there are incomplete paper-based graphs<sup>11</sup>. In general, nurses perform the symptom assessments; however, clinical practice nurses state that they find it a barrier to introduce the USD and to integrate the outcomes of the USD in daily hospice care<sup>12</sup>. Professionals need more support in using and implementing PROs measurements in clinical practice in order to improve patient care<sup>13</sup>. EHealth presents the possibility to remove some barriers<sup>14-16</sup>. Therefore, a USD eHealth application (app) has been developed and implemented since 2015 in hospices in the Netherlands<sup>17</sup>.

The aim of this feasibility study was to explore whether the USD-app supports symptom management by nurses in hospice care. In general, there are eight areas of focus addressed by feasibility studies: acceptability, demand, implementation, practicality, adaptation, integration, expansion and limited efficacy<sup>18</sup>. In 2012, Hjermsstad performed a feasibility study which concluded that electronic assessment of symptoms was well accepted by hospice patients<sup>19</sup>. Despite this study, several areas remain unclear: (a) the demand of the USD-app for hospice patients, (b) the acceptability of the USD-app for hospice nurses, and (c) the integration of the results of the USD-app in symptom management in daily hospice care<sup>18</sup>.

Therefore, this study focuses on the following question: "Is the eHealth USD-application, which assesses hospice patients' symptom intensity, feasible as a basis for symptom management in daily hospice care?" Three sub-questions were formulated: (a) Do hospice patients use the USD-app to self-assess symptom intensity? (b) Is the USD-app acceptable for hospice nurses? And (c) Does the USD-app support hospice nurses in integrating the USD-app data in daily symptom management?

The results of this study will be used to ameliorate the USD-app and its use for symptom management and the implementation strategies used to integrate the use of the USD-app in hospice care to improve symptom management and quality of care in hospice care.

## METHOD

### Design

A mixed-method feasibility study with a two-phased sequential explanatory design was performed from February to June 2017<sup>18,20-22</sup>. The quantitative phase had a cross-sectional design to explore the feasibility areas of demand, acceptability and integration of the USD-app<sup>18,23</sup>. The qualitative phase employed a generic qualitative design to explain the data generated in the quantitative phase on these feasibility areas<sup>22,24</sup>. Both phases were of equal importance and were connected in the intermediate stage in this study<sup>20,21,23,25,26</sup>.

## Population

This study was conducted in professional-driven hospices across the Netherlands. The 14 eligible hospices were a convenience sample of hospices, consisting of members of the Dutch Association of Hospice Care<sup>27</sup> who implemented the USD-app in daily practice.

For the quantitative phase, all nurses from the participating hospices were invited to fill out the questionnaire. In the qualitative phase, a purposeful sample was drawn of two nurses in each participating hospice who were asked to participate in focus groups (FGs) to reach maximum variation in hospices.

In order to be eligible to participate, nurses had to be registered nurses (RN) and work at the included hospice for at least three months to ensure that they had experience with the USD-app. Nurses participating in the FGs were not necessarily the same nurses who filled out the questionnaire.

## Data Collection

The main study parameters were demand, acceptability and integration. Demand was defined as the extent to which the USD-app is actually used by or for patients<sup>18</sup>. Acceptability was defined as the extent that the USD-app is judged as usable and satisfying by hospice nurses<sup>18</sup>. Integration was defined as the extent that the USD-app is integrated in the steps of symptom management, assessment, intervention, monitoring and evaluation in hospice care<sup>18</sup>.

### Quantitative phase

The qualitative data was collected using a self-designed questionnaire. To measure demand, three questions were formulated focusing on the number of patients for whom the USD-app was used and the amount of support needed to use the USD-app (table1).

To explore acceptability, eight usability statements were formulated that focused on the use of the app and the overall satisfaction of the USD-app by nurses. The questions were formulated using the Post Study System Usability Questionnaire designed by Lewis et. al (Q1,2,6,7,10,13 and 19 were used)<sup>28</sup>.

Integration of the USD-app in daily hospice care was measured using 10 integration statements for using the app in different steps of symptom management<sup>4</sup>. These statements focused on introducing the app, using the app for interventions, monitoring and evaluating using the app.

To establish face validity for this specific study, the questionnaire was reviewed by five experts in hospice care<sup>29</sup>. Revisions were made based on consensus. Nine questions were made more specific to prevent misinterpretation, and two questions on well-being were added. Because the use of the USD and the USD-app are intertwined, three knowledge questions about the USD (when, how and why) were added to the questionnaire.

The questionnaire consisted of 48 questions: eight baseline questions, three knowledge questions, three demand questions, 19 seven-point Likert scale (agree-disagree) statements, three yes/no, two multiple choice questions and 10 options to post remarks and improvements.

### Qualitative phase

The results of the quantitative phase were further explored, and underlying reasons were sought to explain demand, acceptability and integration from the nurses' perspective using FGs. The FG used the same items for demand, acceptability and integration that were used in the questionnaire (table1). The topic list consisted of a summary of results of the quantitative phase to start FG discussions.

Semi-structured FGs were performed by a moderator (EdG) who was responsible for facilitating the discussion and presented the participants with a series of questions based on the data retrieved by the questionnaire<sup>30</sup>. The assistant moderator (SH) took notes and retrieved baseline data of the participants<sup>30</sup>. During each FG, member checks were done by giving a summary after each item to check if the information was well understood<sup>31</sup>.

### Other parameters

Hospice data were gathered on the use of the USD-app in months, the use of digital patient records (yes/no) and the time of using the digital patient records in months.

During both phases, baseline data of nurses were gathered: age (years), gender (male/female), position, education and specific palliative care education, working years as a nurse, working years in a hospice, employment in which hospice, and duration of this employment in years.

## Data Analysis

### Quantitative phase

Quantitative data were analysed using descriptive statistics<sup>32,33</sup>. Baseline data were calculated in frequencies and percentages when the variable was categorical and in mean and range when the variable was continuous<sup>32,33</sup>. Percentages were used for displaying the outcomes of the USD demand and the Likert scale questions to discover patterns in the use of the USD-app. Missing data was handled using an available-case analysis approach<sup>33</sup>; all complete and partly complete questionnaires were included in data analysis. The quantitative data were analysed using IBM SPSS Statistics version 24 (IBM, Armonk, United States).

### Qualitative phase

The qualitative data were analysed using content analysis<sup>34</sup>. All FGs were recorded and transcribed verbatim<sup>35</sup>. The following steps were used: (a) reading through data and making margin notes to form initial codes. Then, (b) open coding categories were described. After axial coding, the list of codes was used to (c) create a code tree with categories. Through selective coding, a story emerged that connects these categories<sup>23</sup>. The researchers SH, EdG and MdL were involved in this process<sup>35</sup>. Constant comparison was used to check the 'fit' of incoming data with existing categories<sup>22</sup>. The computer program NVIVO version 11 (QSR International, Doncaster, Australia) was used during the analyses of the qualitative data.

## Study Procedures

In February 2017, the managers of the 14 eligible hospices were approached by email (SH) for inclusion in the study. Participating hospices were asked to provide a contact person to provide baseline information on the hospices; then, the questionnaire was sent to all nurses working at that hospice. The email included extensive information about the study as well as the internet link to the questionnaire.

After the quantitative phase, the nurses of all hospices were invited to participate in a FG. When they indicated in the questionnaire that they wanted to participate in a FG, they were personally contacted by email (SH). When there were no or too few volunteers for a hospice, nurses were invited through the hospice's contact person.



## Ethical Considerations

This study was conducted according to the principles of the Declaration of Helsinki (seventh revision, 2013)<sup>36</sup> and in accordance with the Medical Research Involving Human Subjects Act (WMO)<sup>37</sup>. Under Dutch law, this study is exempt from approval from an ethics committee. The participant received no incentives or compensation for participating in this study. All participants had the considered minimal burden of invested time and energy.

Local approval was obtained from the management of the participating hospices. Filling out the questionnaire and/or participating in the FG was considered informed consent. Data were gathered anonymised and coded.

## RESULTS

In total, 11/14 hospices participated and 85/151 participants responded. Of these, five were excluded because they were not nurses (fig.1). Of the included nurses, 64/80 (80%) completed all the questions in the questionnaire. The participating hospice used the USD-app for a mean of 15 months and nine hospices used electronic patient records (82%) with a mean use of 34 months.

A total of eight nurses participated in three FGs from six different hospices (55% of all hospices) (2-5 participants per FG). Reasons for hospices not participating were distance to the location of the FG, vacation and low occupancy (fig.1).

Of the 80 nurses who filled out the questionnaire, 76 were female (96%) with a mean age of 50. Of these nurses 51% were RN, 42% RN with a bachelor degree and 7% had a higher education. Of all nurses, 69% had specific palliative care education. The participants had a mean of 24 years' work experience, of which nine years had been spent in a hospice (table2).

All FG nurses were female, with a mean age of 49. The education distribution was 38% RN, 38% RN with a bachelor degree and 25% higher education. Of these nurses, 75% had specific palliative care education. The mean work experience was 21 years of which 10 years was spent in a hospice (table2).

The USD in general was used for: symptom assessment (94%), interventions (63%), monitoring symptoms (69%) and evaluating symptoms (70%). In the questionnaire, participants stated that they knew why (85%) and how (81%) to use the USD.

FG nurses recognised these outcomes although there was a presumption that the USD was used to measure quality of care in hospices.

## Demand

In total, 62/80 participants (78%) had used the USD-app. The app was used for 332/412 (75%) of the admitted patients. Of these 332 patients, 13% could use the app completely independently, 10% with instruction and 51% of the patients needed physical help to use the app. If patients were unable or unwilling to self-report their symptoms, the USD was completed by either an informal caregiver (3%) or by professionals (34%), mostly by nurses (87%) (fig.2).

Qualitative findings showed that the USD-app was used to start conversations about symptoms. Furthermore, the use of the USD and the use of the USD-app unmistakably intertwined with each other. FG participants recognised that most patients needed help to use the USD-app. Whether patients were able to use the app independently, with help or not at all, was mostly decided by nurses (table3)

## Acceptability

In the questionnaire, 47/80 participants (59%) agreed that they had been adequately trained in the use of the USD-app and 39% found it easy to learn. Whether mistakes could easily be recovered, 20% was somewhat neutral. Of the participants, 60% found that there were sufficient facilities to use the app. In contrast, 8% had technical problems using the app. Over half (56%) found that outcomes were easy to find, and only 1% found that the outcomes were not displayed clearly. Overall, 63% were satisfied with the USD-app (table4)

FG nurses mentioned that there was a difference between the app use by patients and professionals. For professionals, it was easy; for patients, it was more difficult. Influencing factors were the complexity of the formulated questions and the 11-point numerical scale, which was difficult to understand. Questions about the psychological and spiritual dimension, specifically, were difficult to answer for patients. Nurses stated that the process of reversing mistakes was cumbersome when outcomes were saved.

Some technical improvements were proposed for the use by patients, like using a faces scale. However, other nurses stated that for some patients, it was helpful to see the scale on the app. One hospice had problems with the wifi connection at the bedside and chose to use the USD paper version instead (table3).

## Integration in symptom management

### Introduction

Of the participants, 40% (32/80) had introduced the app to fewer than 10 patients; in contrast, 20% introduced the USD-app to more than 30 patients. Only 24% of the participants introduced the app to all patients admitted. For 55%, however, this depended on the condition of the patient. Nurses found the introduction for the USD-app easy (35%) and felt comfortable (34%). However, 43% stated that they could introduce the USD-app in a way that patients would want to use the app (table4).

FG nurses mentioned that introducing the app is complex, especially at admission. Reasons mentioned were the fact that patients get extensive information at admission and have minimal energy. Hence, nurses feel that they are overburdening patients and that experience is needed to introduce the USD-app in a natural way. Four nurses stated that introduction can be influenced by the nurses' attitude towards the USD introducing the app. The nurses mentioned that they decided to which patients to introduce the app (table3).

### Intervention

According to 55% (44/80) of the participants the outcomes of the USD-app are used in daily care, mostly during multiprofessional team meetings (MTMs). The use of outcomes in daily care wasn't easy (7%). Participants (57%) found that the USD-app gave insight into symptoms. Nurses (48%) agreed that the app was used to deploy appropriate interventions, but not rapid interventions, specifically (31%) (table4).

All FG nurses stated that the app provided insight into symptom intensity. They mentioned that rapid interventions were not linked to the use of the app, but that it helps deploying appropriate interventions. Because of the USD, patients can play an active role in their care and nurses are enabled to get in touch with their patients. Knowledge and competences are needed to translate the outcomes of the USD into appropriate interventions (table3).

### Monitoring

Insight into the course of symptom intensity was supported by the app according to 45/80 (56%), although 45% felt it supported insight into patients' well-being (table4).

The FG showed that the app provided a clear overview which ameliorated insight into the course of symptom intensity. The overview was used to involve the patient and support MTM discussions. The frequency of app use is essential for monitoring the course of symptom intensity and well-being. However, the course of the social and spiritual questions were harder to interpret due to reverse scoring. The app improved insight into the course of symptoms in comparison to the paper version (table3).

### Evaluation

The USD-app supported 35/80 (44%) of the participants in evaluating the effect of interventions, and 48% found that the app supported evaluating the well-being of the patients (table4).

FG nurses stated that evaluation in general is a concern in most hospices. Evaluation mostly takes place during MTMs and although some hospices used the USD-app outcomes, most nurses did not consciously include the outcomes in the evaluation process. Nevertheless, several nurses mentioned that the app is an appropriate tool to use during evaluations, particularly with the patient. Nurses stated that evaluation requires continuous reflection and competences (table3).

## DISCUSSION

The USD-app is feasible as a basis for symptom management in daily hospice care. The USD-app demand was that it was used for more than 70% of admitted patients. More than 50% of the patients needed physical help, and only 13% used the app completely independently. The acceptability of the app is high (63%), and it improved insight into the course of symptoms and the patients' well-being although some improvements were mentioned. In most hospices, the app is not completely integrated into daily care. Nurses specifically found the introduction of the app and the evaluation of interventions difficult. Influencing factors are knowledge, competences and attitudes of the nurses using the USD-app.

Challenges for using the USD-app were are misinterpretation of reverse scoring, assessing patients with impaired communication and lack of time. Most of these challenges arose in other studies as well<sup>12,38</sup>. According to the majority of participants, the numerical

rating scale (NRS) was difficult for patients to use and the reverse scoring was hard to interpret. There are multiple studies that compare self-reporting scales used to assess symptom intensity<sup>11,39,40</sup>. The patients' preference for scales differs between populations, although it is recommended that one scale is used per patient because of comparability<sup>39</sup>.

Another barrier for using the USD-app was that over 50% of the patients needed assistance. This is in line with the study of Hjermstad, which concluded that reduced performance status of patients reduces compliance and increases the need for assistance of the computer-based self-assessment<sup>19</sup>. In this study, assistance was mostly a conscious choice of nurses to initiate a conversation about symptoms concurrently. Although a lack of time was identified as a barrier for using the USD-app, this is also in line with previous studies<sup>12,41</sup>.

The use of the USD-app to identify symptoms was considered either indispensable or a burden. The difference in opinion and attitude is known in literature about using the ESAS<sup>12</sup>. However, previous study showed that using a computer-based self-assessment tool for patients versus those of the control group, that significantly more symptoms were addressed in the intervention group<sup>42</sup>.

The use of an eHealth application requires additional competences of nurses. The competences, clinical knowledge and communication skills of nurses are also indispensable for eHealth<sup>43</sup>. Our study showed that competences of nurses in general and in symptom management are linked to the use of the USD(-app). However, it is known from a previous study that professionals still rarely or never look at a patient's outcomes (11% of nurses) seven years after implementation<sup>12</sup>. The study of Houwelingen et al. suggest that to reap the benefits of patient-centred care, the use of patients' assessment tools must receive equal priority as other routines, and require sufficient time, space and competence like communication skills<sup>44</sup>. This conforms to added value for using the USD-app for patients is only noticeable when it is well adopted.

For a successful implementation of PRO measures, the educational component prior to the implementation is crucial<sup>13</sup>. Although the participants in our study agreed that they were adequately trained, the use of PRO were not always integrated in daily practice. One of the main reasons for this was the attitude of the nurses toward the USD(-app) and the attitude of other members of the multiprofessional team (MPT). The attitude of nurses deciding for patients is similar to a "gatekeeper attitude" in research, which is a protective or obstructive attitude of a healthcare professional that denies the patient the right to decide<sup>45,46</sup>. This attitude is also seen in self-management support, which states that nurses take the lead and

determines which topics will be discussed with patients<sup>47</sup>. The responsibility of caring for vulnerable patients can lead to an overbearing attitude like the “gatekeeping” attitude seen in this study. This attitude must be reversed to include shared decisionmaking<sup>48</sup> with patients for the USD-app to be used properly and integrated in daily hospice care to provide actual patient-centred care.

### Strengths and limitations

The strengths of this study include the response rate of over 50% for an internet questionnaire and the mixed method design, enabling an in-depth exploration of the feasibility of the USD-app. In addition, the data analysis was performed by multiple researchers to ensure trustworthiness and eliminate information bias. Although the sample in the FG was small, and not all hospices were represented, the characteristics were similar to the participants of the questionnaire. The characteristics of this study are similar to previous studies conducted in hospice care worldwide<sup>49,50</sup>.

### Implications for clinical practice and future research

The implementation of the USD-app should be embedded in the implementations of symptom management, and the app should be used in all four steps to ensure a full integration of the results of the app. Knowledge regarding the USD and symptom management, competences in general, conversation techniques, awareness of nurses of their gatekeeper attitude, changing this attitude and the full support of the MPT for using the USD-app creates an environment where the use of the USD-app could be fully adopted.

It is also recommend that nurses learn the competences and communication skills associated with eHealth. This should be embedded in nursing education because the use of eHealth will increase in healthcare. The possibility for using additional scales in the USD-app should be explored in future research.

### Conclusions

The USD-app is feasible as a basis for symptom management in daily hospice care. The USD-app demand was that it was used for more than 70% of the admitted patients. The acceptability of the app is high, but there are some improvements that can be done. The USD-app is not completely integrated into daily hospice care in most hospices. A successful integration and adoption depends on knowledge, competences, the nurses' attitude and support from the MPT.

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## TABLES AND FIGURES

Table 1: Main Parameters in Questionnaire

Demand questions:
How many patients are currently admitted in the hospice?
For how many of these patients is the USD-app used?
Who completed the USD-app, and what was the amount of support needed?
Acceptability statements (7 point Likert scale):
Adequately trained in the use of the USD app
Easy to learn
Mistakes could easily be recovered
Sufficient facilities
No technical problems
Outcomes were easy to find
Outcomes were displayed clearly
Overall satisfaction USD app
Integration statements (7 point Likert scale):
Introducing was easy
Introducing in a way that people want to use the USD app
Insight in symptoms
The use of outcomes in daily care
Appropriate interventions
Rapid interventions
The course of symptoms
The course of well-being
Evaluating interventions
Evaluating well-being

Figure 1: Flowchart

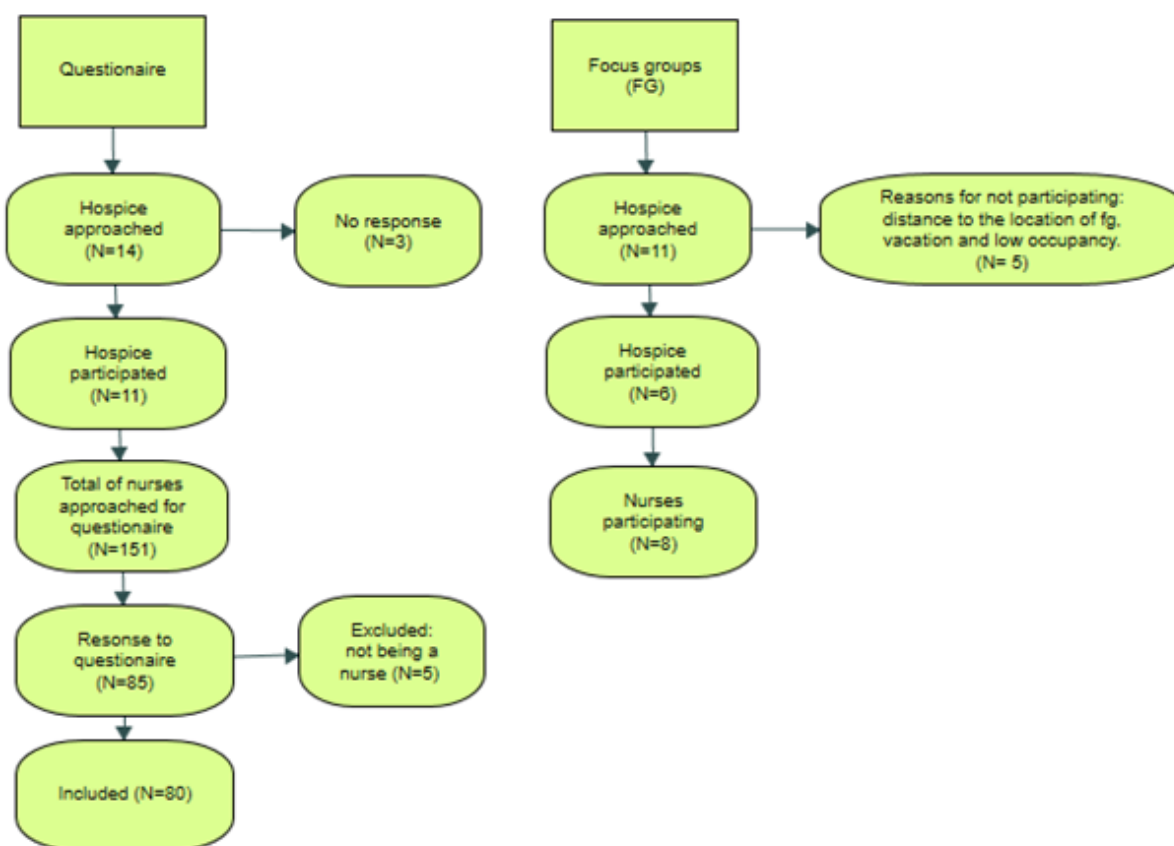
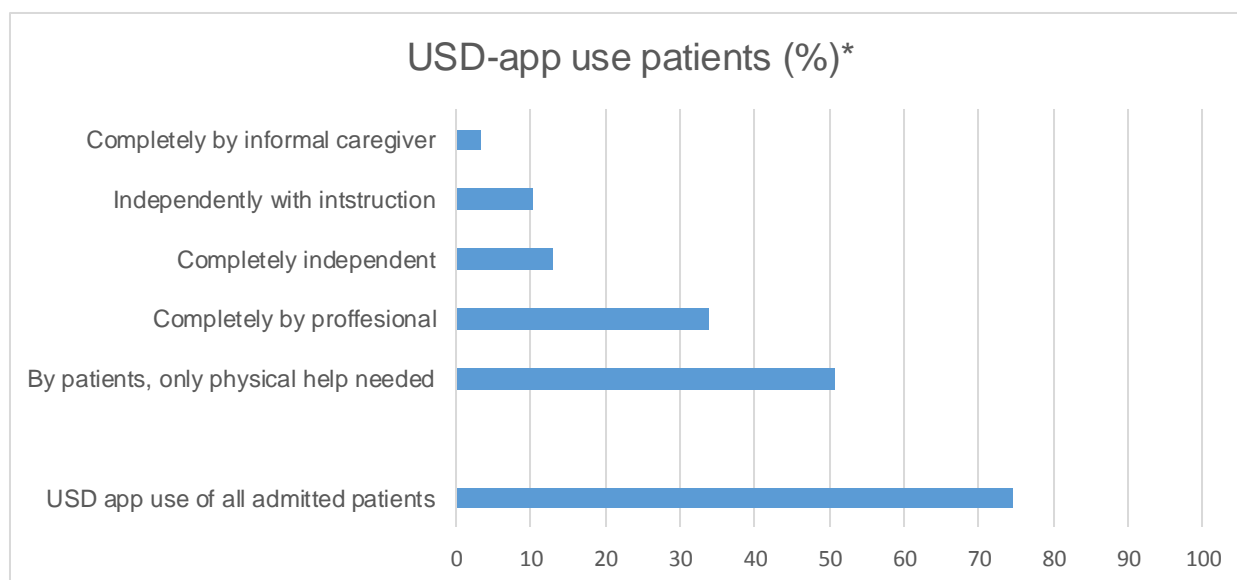


Table 2: Baseline

Baseline data participants		
	Questionnaire	FG (N=3)
<b>Total N participants</b>	<b>80</b>	<b>8</b>
<b>Total N hospices</b>	<b>11</b>	<b>6</b>
<b>Female (%)</b>	<b>76 (96,2)</b>	<b>8 (100)</b>
<b>Mean age (range)</b>	<b>50 (27-65)</b>	<b>49 (41-58)</b>
<b>Education</b>		
Registered nurse (%)	36 (50,7)	3 (37,5)
Registered nurse bachelor degree (%)	30 (42,3)	3 (37,5)
Higher education* (%)	5 ( 7,0)	2 (25,0)
<b>Advanced education (%)</b>	<b>49 (69)</b>	<b>6 (75)</b>
None (%)	22 (31)	2 (25)
<b>Mean Work experience in years (range)</b>	<b>24,4 (0-42)</b>	<b>21,3 (12-27)</b>
<b>Mean Work experience in hospice in years (range)</b>	<b>8,9 (0-24)</b>	<b>9,8 (6-17)</b>

FG, Focus groups; \*Higher education: equally or higher than bachelor degree.

Figure 2: Demand USD-app Use



\* For some patients, both the patient and a healthcare provider completed the USD so the percentage can be >100%.

Table 3: Quotes Focus Groups

	Focus group (FG) and Participant (P)	Quote
Demand	FG1, P3	<i>"In order to use the app for patients themselves, it's simply not very convenient"</i>
	FG 2, P4	<i>"We are not very easy to let go of things, so we sometimes underestimate people that they could do it themselves"</i>
Acceptability	FG 3, P8	<i>"For psychosocial and spiritual questions, I often hear that people say that they find it hard"</i>
	FG 2, P5	<i>"For us yes it was easy to learn, I think it's very user-friendly, but what you say, especially older people and people with a mental disability, it's a difficult app"</i>
Integration	FG 1, P1	<i>"It is indeed seen as a kind of burden yes, because they do not have it all in check when they are admitted and then we have more to explain"</i>
	FG 3, P8	<i>"Without the usd, those interventions would also be used, but the usd helps to substantiate it"</i>
	FG 3, P7	<i>"I'll show that overview, quite regularly to patients"</i>
	FG 2, P5	<i>"Mainly the multidisciplinary team meeting (MTM) is the evaluation"</i>

Table 4: Likert-scale Outcomes Questionnaire (N=80)

	Questions	Responses, N (%)								NA	Missing
		1	2	3	4	5	6	7			
		entirely agree	mostly agree	somewhat agree	neutral	somewhat disagree	mostly disagree	entirely disagree			
<b>Acceptability</b>											
	Adequately trained in the use of the USD app	24 (30)	23 (29)	11 (14)	5 (6)	2 (3)	2 (3)	0 (0)	1 (1)	12 (15)	
	Easy to learn	31 (39)	23 (29)	6 (8)	4 (5)	0 (0)	3 (4)	0 (0)	1 (1)	12 (15)	
	Mistakes could easily be recovered	22 (28)	19 (24)	8 (10)	8 (10)	4 (5)	3 (4)	2 (3)	2 (3)	12 (15)	
	Sufficient facilities	27 (34)	21 (26)	8 (10)	4 (5)	4 (5)	3 (4)	0 (0)	1 (1)	12 (15)	
	No technical problems	18 (23)	24 (30)	4 (5)	8 (10)	7 (9)	4 (5)	2 (3)	1 (1)	12 (15)	
	Outcomes were easy to find	29 (36)	16 (20)	12 (15)	3 (4)	1 (1)	2 (3)	0 (0)	0 (0)	17 (21)	
	Outcomes were displayed clearly	26 (33)	16 (20)	14 (18)	6 (8)	1 (1)	0 (0)	0 (0)	0 (0)	17 (21)	
	Overall satisfaction USD app	14 (18)	25 (31)	10 (13)	10 (13)	0 (0)	2 (3)	1 (1)	1 (1)	17 (21)	
<b>Integration</b>											
<b>Introduction</b>	Comfortable introducing USD app	10 (13)	17 (21)	14 (18)	15 (19)	3 (4)	3 (4)	0 (0)	1 (1)	17 (21)	
	Introducing was easy	13 (16)	19 (24)	12 (15)	14 (18)	2 (3)	2 (3)	0 (0)	1 (1)	17 (21)	
	Introducing in a way that people want to use the USD app	14 (18)	20 (25)	11 (14)	13 (16)	3 (4)	1 (1)	0 (0)	1 (1)	17 (21)	
<b>Intervention</b>	Insight in symptoms	26 (33)	19 (24)	12 (15)	5 (6)	0 (0)	0 (0)	0 (0)	1 (1)	17 (21)	
	The use of outcomes in daily care	16 (20)	19 (24)	12 (15)	9 (11)	5 (6)	1 (1)	0 (0)	1 (1)	17 (21)	
	Appropriate interventions	12 (15)	26 (33)	12 (15)	9 (11)	3 (4)	0 (0)	0 (0)	1 (1)	17 (21)	
	Rapid interventions	8 (10)	17 (21)	17 (21)	15 (19)	3 (4)	1 (1)	1 (1)	1 (1)	17 (21)	
<b>Monitoring</b>	The course of symptoms	31 (39)	14 (18)	13 (16)	4 (5)	0 (0)	1 (1)	0 (0)	0 (0)	17 (21)	
	The course of well-being	24 (30)	12 (15)	14 (18)	9 (11)	2 (3)	2 (3)	0 (0)	0 (0)	17 (21)	
<b>Evaluation</b>	Evaluating interventions	13 (16)	22 (28)	15 (19)	8 (10)	1 (1)	2 (3)	1 (1)	1 (1)	17 (21)	
	Evaluating well-being	12 (15)	26 (33)	13 (16)	6 (8)	1 (1)	3 (4)	1 (1)	1 (1)	17 (21)	

USD app, Utrecht Symptom Dairy application; NA, Not applicable.