Digital Health and Informatics Innovations for Sustainable Health Care Systems
J. Mantas et al. (Eds.)

doi:10.3233/SHTI240347

Towards a Learning Health System for Symptom Management in Hospice Care

Marieke MASSA[a,1], Marijke A. DERMOIS[a], Jennifer CAFFAREL[a], Christine M. CRAMER-VAN DER WELLE[b], Dianne K.E. BOXMAN[b], Everlien DE GRAAF[c], Saskia S.C.M. TEUNISSEN[c] and Jurrian VAN DER WERF[a]
[a] *Department of Research and Development, Netherlands Comprehensive Cancer Organisation, Utrecht, The Netherlands*
[b] *Dutch Institute of Palliative Care, Utrecht, The Netherlands*
[c] *Centre of Expertise in Palliative Care, Julius Center for Health Sciences and Primary Care, University Medical Centre Utrecht, The Netherlands*
ORCiD ID: Marieke Massa https://orcid.org/0000-0001-9109-5786

Abstract. The reuse of real-world symptom monitoring data is essential in improving the quality of hospice care. A framework for achieving this is a Learning Health System, in which the development of a well-defined dataset is essential. This paper discusses the challenges in the design of a comprehensive dataset, focusing on variations in two electronic health record systems and divergent care processes.

Keywords. Hospice Care, Symptom Management, Learning Health System

1. Introduction

Hospice care aims to prevent suffering across physical, psychological, social, and spiritual dimensions. Symptom monitoring, facilitated by tools like the Utrecht Symptom Diary-4 Dimensional (USD-4D) [1], is crucial for appropriate care. A Learning Health System (LHS) for symptom management stimulates this, utilizing real-world data for continuous improvement [2]. Previously, we explored an LHS in six hospices using the same Electronic Health Record (EHR) implementation, focusing on collection and presentation of symptom management data. Now, we aim to integrate a second EHR and outline challenges in dataset design due to varying care processes and EHR specifications.

2. Methods

To expedite the implementation of an LHS without imposing additional registration demands on caregivers, we chose to formulate a dataset based on existing content within the EHRs in use, through a series of sequential steps. First, the results of the pilot study were used to establish an overview of all relevant data items. Secondly, in a multidisciplinary setting involving palliative care experts and informaticians, deliberations took place to determine the relevance of each item. A distinction was made

---

[1] Corresponding Author: Marieke Massa; E-mail: m.massa@iknl.nl.

between items with direct impact on daily individual care and additional items required for research purposes. Data items were mapped on international information standards if possible. Thirdly, the dataset was mapped on the second EHR. Analyses of the system's standardized input fields were complemented with care process mapping with three hospices to learn if there were differences in how these items were used or interpreted.

3. Results

The comprehensive dataset contains patient characteristics, health-related patient data, data on symptom burden (USD-4D) and problems, and data on care needs and support in the four dimensions of palliative care [1]. Studying the retrieval of certain data items from the new EHR (EHR2) revealed difficulties not present in the EHR from the initial pilot (EHR1). We discuss three examples. First, EHR1 provides a selection list for the active diagnosis with optional further explanation in a separate field. EHR2 utilizes free-text fields for 'medical history', with optional use of a terminology standard. It may include events that are no longer active. In the interviewed hospices using EHR2, medical history is either entered by a hospice caregiver or automatically extracted from the EHR of a geriatrician, where in EHR1 hospices this is always filled out by a hospice caregiver.

The second example is the USD-4D instrument, implemented via a template available for all hospices using EHR2. The role of the individual (patient, relative or caregiver) reporting on the symptoms cannot be registered here, whereas this is registered in EHR1. Thirdly, the dataset includes a measure to verify whether attention has been paid to the four dimensions of palliative care. EHR1 designates input fields for these dimensions, allowing for verification if these fields are empty. EHR2 lacks such fields.

4. Discussion and Conclusions

The discrepancies between both vendors' systems pose the main challenge in implementing an LHS. The difference in implementation of the USD-4D instrument exemplifies the risk of losing detail when choosing to combine the EHRs: conducting an analysis of reported symptoms, categorized by role of the reporter, becomes unfeasible and different detail levels make EHR comparisons challenging. The other two examples underscore the complexity of extracting certain data elements, necessitating free text processing and making assumptions about where information is registered in an EHR.

A common data model designed with and mandated by caregivers, that all EHRs can, or even must comply with, is required in order to effectively develop an LHS for symptom management in hospice care.

References

[1] De Vries S, Lormans T, De Graaf E, Leget C, Teunissen S. The Content Validity of the Items Related to the Social and Spiritual Dimensions of the Utrecht Symptom Diary-4 Dimensional From a Patient's Perspective: A Qualitative Study. J Pain Symptom Manage. 2021;61(2):287-294.E2. doi:10.1016/j.jpainsymman.2020.07.036.

[2] Post AR, Burningham Z, Halwani AS. Electronic Health Record Data in Cancer Learning Health Systems: Challenges and Opportunities. JCO Clin Cancer Inform. 2022 Mar;6:e2100158. doi: 10.1200/CCI.21.00158. PMID: 35353547; PMCID: PMC9005105.