

Assessing Methods to Model Patient-Centric Care Pathways across Multiple Healthcare Systems

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Abstract—Clinical pathways have been promoted to maximize care coordination. Over the last decade, they have developed into patient-centric pathways, including the patient's needs and expectations of future health care. Integrated patient-centric pathways facilitate and encourage the coordination between multiple levels of care. Electronic Health Records (EHRs) contain information that could support integrated, patient-centric pathways. This paper aims to identify the challenges of modelling patient-centric pathways spanning primary and specialist care and provide guidelines for meeting those challenges. The study results show the lack of a standard definition of an integrated, patient-centric pathway and the various methods used to describe them. Finally, the study provides recommendations for a new approach for modelling EHR-supported, patient-centric pathways across the care continuum.

Keywords-patient-centric care; pathway modelling; integrated care; electronic health records.

I. INTRODUCTION

A rise in life expectancy has increased the need for more complex health care as the number of patients with multiple chronic conditions increases [1]. More resources are needed to provide the same level of care, challenging the health care services available for other vulnerable groups, such as young adults struggling with mental illness. Simultaneously, innovative drug treatments, therapies, and technology allow patients to receive care in their own homes. Health literacy amongst the general population, developed through media, has increased patient expectations [2] and changed the relationship between the patient and the healthcare provider and the understanding of patient-centred care [3]. Clinical pathways have been promoted as a response to meet the patient's needs and expectations of future health care and maximize care coordination [4]. Extensive research on implementing clinical pathways has also improved quality of life and reduced morbidity [5].

The health care sector has been through several reforms to implement pathways for different illnesses. Various terms for clinical pathways have been used, such as "clinical guidelines", "patient pathways", "care pathways", or "integrated care pathways" [6][7]. A common understanding defines a *clinical pathway* as standardized steps to rapidly diagnose the patient's illness and initiate treatment [8]. Clinical pathways can have different aims, such as integrating multidisciplinary teams (horizontal integration) or integrating services across primary, secondary and tertiary care (vertical integration) [9]. Care pathways are often seen as a "care coordination" tool to optimize the sequence of healthcare interventions performed by multidisciplinary teams across disease groups and health settings [7]. Though the terms are used interchangeably, care integration is aimed "to facilitate and encourage the coordination between levels of care" [10]. The term integrated care pathways, understood as vertically integrated, will be used in this paper.

The use of pathways as a "clinician-directed, patient-focused response" to coordinate care [11] is challenged by the changing understanding of what patient-focused care, also referred to as "patient-centred", "personalized", or "patient-centric" care, is. Conventionally, the patient focus has been interpreted within a biomedical framework, where the patient's illness is defined by a set of signs and symptoms [12]. In the late 1960ies, the patient focus included "providing information to the patient" [13]. Over time, the understanding of patient-centric care developed to include taking into account the whole person, exploring the patients' experience and ideas about the problem as a resource to guide the interaction, sharing power and agreeing on managing their illness [14]. Recent research, such as by Rand, Dunn, Slade, Upadhyaya, and Sheehan [15], argues that patient experience should be viewed as evidence in healthcare decision-making. Together, the understanding of "patient-centric" and the "integrated care pathways" defines the concept of patient-centric, integrated care pathways for the context of this paper.

Whereas the patient needs and demands can be said to "force the integration of services", the supply side, including technology and information systems, may facilitate it [10]. Access to Electronic Health Records (EHRs) is considered an essential component [1] of supporting patient-centric, integrated care pathways [16]. Guided by a multilevel, socio-technical lens, healthcare delivery can be represented on a system level (macro), a meso level, concerned with regional and local health services and community factors, and a micro level, representing every-day practices and patient perspectives [17]. At a macro level, sharing information can allow for better planning of services [18] and, at a meso level, contribute to integrating professional teams and healthcare organizations. At a micro level, increased access to EHRs could support the empowerment of patients and improve the quality of care [10].

In general, many approaches, modelling methods and tools have been used to describe pathways in healthcare; several adapted from other industries [19]. Traditional process-modelling methods, such as Business Process Modelling Notation (BPMN) [20] and Event-driven Process Chain (EPC) [21], have been used to describe work processes at a macro or meso level. Lean Design principles have been used to model meso-level pathways in quality improvement projects [22]. Key Service Design concepts have been used for transformative healthcare service research, viewing knowledge of patients, their families and healthcare professionals as essential to understanding the healthcare service needs. The Service Design approach has also evolved to address technology-enabled services [23][24]. "Customer Journey Mapping" (CJM), referred to as "Patient Journey Mapping" (PJM), when applied in healthcare, represents a micro-level, patient-centric perspective of the health care service based on the patient narrative [25]. Customer Journey Mapping Language (CJML) is a more recently developed framework for customer journey analysis [26]. Data-driven pathway modelling, such as Process Mining, has been used to support building pathways by using existing data from EHRs to display the actual patient pathway [27]. Unified Modelling Language (UML) has provided a more system-centric modelling method, connecting stakeholders, tasks and system intended functionality [28].

While different methods are available for modelling each of the health service levels, to the best of our knowledge, there is no single modelling tool currently available that collectively addresses the macro, meso and micro levels. This paper provides a general overview of the research and methodological guidance on modelling integrated, patient-centric pathways across multiple levels of care by (1) identifying the challenges of modelling patient-centric pathways spanning primary and specialist care and (2) providing recommendations for dealing with these challenges.

The rest of this paper is organized as follows. Section II describes the literature search, and Section III describes different approaches to describe integrated patient-centric pathways. A discussion on how to combine methods to meet the challenges of modelling cross-sectional pathways is

outlined in Section IV before concluding the paper in Section V.

II. METHODS

A literature search was conducted using the PubMed and Scopus databases, restricted to the years 2006-2022. The databases were chosen to cover both the medical and technological sides of pathway modelling. The inclusion criteria for the search were studies describing how patient-centric pathways were modelled, published in English. This initial, broad search resulted in keywords used for a search in title, abstract and keywords narrowed down by using the terms "patient", "pathway" and "journey" combined with variations of the terms "centric" and "centred" to capture articles with a patient-centric approach when describing the pathways. To ensure the relevance of the articles to the problem described regarding care integration the terms "integrated", "coordinated", "collaborative", and "multidisciplinary" were added. Finally, variations of the terms "modelling", "developing", "mapping", "constructing", "framework", or "method" were added to find literature that described pathway-modelling methods.

The PubMed search string was: ((patient-centered care[MeSH Major Topic] OR ("patient-centric care")) AND ((Delivery of Health Care, Integrated) OR coordinated* OR collaborative OR multidisciplinary) AND (pathway* OR journey*)) AND (model* OR framework OR method*) AND (developing OR mapping OR constructing). The Scopus search string TITLE-ABS-KEY(("patient-centered care" OR "patient-centric care") AND (integrated OR coordinated OR collaborative OR multidisciplinary) AND (pathway* OR journey*)) AND (model* OR framework OR method*) AND (developing OR mapping OR constructing)) returned 31 articles, none which met the inclusion criteria. The terms related to integrated care were limiting the number of results and therefore removed. Based a search for relevant keywords to capture articles in Scopus regarding modelling methods two new terms were added: "pathway mapping" and "journey mapping". The final Scopus search string was: "pathway mapping" OR "journey mapping" AND patient AND pathway OR journey AND model* OR framework OR method* AND developing OR mapping OR constructing.

III. RESULTS

The search returned a total of 127 journal articles. The lack of a common definition of an integrated, patient-centric pathway and standards for modelling them risks biasing the literature search results. The variation in terminology is characteristic of an emerging intersectional topic such as designing patient-centric care pathways spanning multiple healthcare levels, possibly supported by digital tools or/and EHR data. Conceptually, similar research can be reported in very different disciplines.

The articles were screened based on their abstracts. The inclusion criteria were: (1) methods for modelling were discussed (2) patients were engaged in developing the pathway models and (3) the pathways included multiple healthcare levels. The article had to include at least two of the criteria to be included. Clinical guidelines describing a

workflow for a specific diagnosis in a hospital setting, though common in pathway research, were excluded as the research described in this paper focuses on integrated, patient-centric pathways across the care continuum.

The first criteria resulted in 88 articles being excluded. After full-text reviewing 39 articles, 28 were excluded, as they did not satisfy at least two of the inclusion criteria. In addition, two were excluded as they were by the same authors, describing the same methods, only used for different diseases. The remaining nine were included in this study [29][30][31][32][33][34][35][36][37].

Models on all of the macro, meso and micro levels presented earlier were represented in the research. Four studies discussed issues in regards to modelling pathways across multiple healthcare levels [32][34][36][37]. All the included studies described patients as being engaged in developing the pathways. Three studies used a participatory research design [30][35][37], actively involving patients throughout the development process, representing the shift to a more holistic patient-centric care. In these studies, data to build the pathways were obtained through observations, interviews, focus groups, surveys and workgroups, engaging patients and their care providers, and the clinicians' participation secured the meso-perspective in the pathway. Only one study used data from the EHR in a data-driven approach that contributed to understanding the information flow throughout the pathways [33]. The approach included using several IT artefacts, such as a smartphone app and home-based medical equipment, to provide data to an EHR for clinicians.

The patient-centric pathways, or patient journeys, were modelled using a variety of approaches, from general illustrations [29][34], spreadsheets [35] or diagrams [37], to some variation of a flowchart [29][32][34] or patient journey map [35]. One article described the use of software-development methodologies to design pathways [30]. Data gathered through review of medical charts was used to generate pathways in one article [36]. Two articles discussed methodological issues without presenting a model [31][33]. Process mining was discussed to complement pathway mapping, deriving patient pathways from electronic health records [33]. None of the articles included in the study presented the use of digital modelling tools develop the pathways.

Five studies mentioned digital technology and EHR data as critical components for successfully implementing patient-centric pathways [29][30][33][34][35]. Furthermore, the studies discussed how digital technology could be integrated into the patient pathway to support the exchange of health data in real-time, opening a proactive approach to care. One study developed system supported pathways through a secured web-based platform, including functions covering the end-to-end care process [30].

Three studies reported that existing patient pathway mapping tools required modifications to reflect patient journeys across multiple healthcare settings [30][35][37].

When developing the pathways, different objectives and perspectives on patient care also caused tension and obstacles between different levels of care, challenging the

collaborative process of designing patient pathways [32]. Others described how a patient-centric approach to pathway modelling challenged knowledge silos, helped bridge disciplinary boundaries and provided a possibility to develop a common language around the multi-organizational pathway [35][37]. It was also argued that an EHR-supported, data-driven, or at least data-supported, patient-centric pathway could improve the continuity of care in a disaster situation such as the COVID-19 pandemic, as it would have permitted more precise management of the emergency response undertaken in primary and specialist care [34].

IV. DISCUSSION

The first objective of this paper was to assess the challenges of modelling patient-centric pathways across multiple healthcare levels. Though the issue has been described theoretically in several studies, this paper's literature search neither provided methods to develop such pathways nor guidelines to do so. Consequently, self-designing a method is considered a suitable approach for the second objective of this paper; providing recommendations in the form of guidelines for how to deal with these challenges. The characteristics of patient-centric, integrated, EHR-supported care pathways, as described earlier, become requirements for the recommended modelling approach.

On the macro and meso levels, process modelling, when using a common language and easily understandable notation, has been documented to offer a greater understanding of different stakeholder perspectives across disciplines and organizational levels in healthcare [19]. Though no relevant research was found on using process modelling methods to model integrated, data-supported patient-centric pathways as defined in this paper, process modelling is considered beneficial to enhance communication and gather consensus for work processes at a macro and meso level and across multiple healthcare organizations.

At the micro level, the Service Design approach, the Lean method and PJM all base the pathway models on patient narratives. Co-designing pathways with patients is a central element in these methods to empower patients. Including patients in the analysis and design of care pathways could also help identify gaps in the integrated care provision. However, PJM does not necessarily capture the clinical side of the patient pathway. Combining the patient perspective with principal activities in the clinical workflows as they are seen in the eyes of the healthcare professionals into one pathway model can aid in creating a shared understanding of the patient-centric pathway as a whole. Figure 1 presents a simple model using a combination of BPMN and CJML to develop a conceptual model to illustrate the complexity of modelling integrated, patient-centric care pathways. The model presents the start of care; a patient's initial meeting with their general practitioner (GP), the referral to specialized care, the health care levels involved, the healthcare professionals' activities, and the IT systems that supports these activities.

Digital modelling tools, such as MEGA, Qualiware X, BiZZdesign or Essential Project, are available for modelling

pathways. Such tools allow sharing and reusing of models and can balance the trade-off between overview, comprehensiveness and detail. Recent expansions of BPMN, such as BPM+ Health, could add the possibility of deconstructing conceptual pathway models into more precise, possibly executable models, “connecting” the Patient

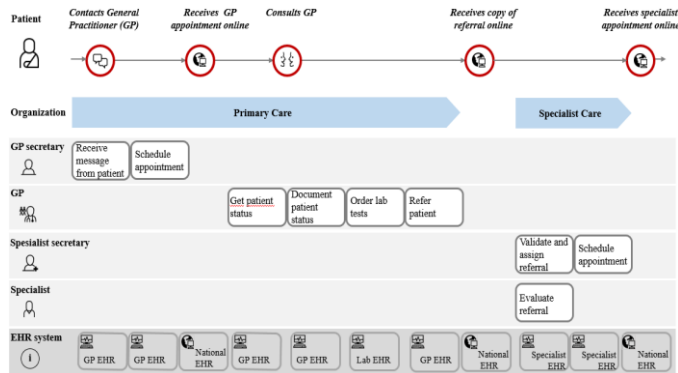


Figure 1. Example of a conceptual model of an patient-centric, EHR-supported pathway using BPMN and CJML. Adapted from [38].

Journey Map and BPMN process model to the EHR data [16]. This would represent the leap from a conceptual patient-centric pathway model to a digital one.

V. CONCLUSION

The results from the literature search of this study present the variety of methods used to describe patient pathways and how the lack of a standardized methodological approach challenges the call for healthcare services transformation into more integrated, patient-centric care. We have suggested guidelines to meet those challenges, emphasizing the need to integrate the different stakeholder views and EHR data into one pathway model to provide an overview of essential elements in the pathway from a macro, meso and micro level perspective.

Combining BPMN, CJML, and BPM+ methods can help overcome the limitations of a specific method and provide a different healthcare research approach that meets the request from earlier research to design healthcare service experiences that qualify patient-centeredness, care integration and the use of EHR data to support the pathways. Further work is needed to develop method formalism, improve the visual presentation of the models' different perspectives, and exploit the potential of digital tools and reusable patient pathway templates. Finally, there is a need to explore how data from EHRs, regardless of where the EHR is located, can support integrated, patient-centric pathways.

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