

Understanding Patient Pathways in the Context of Integrated Health Care Services - Implications from a Scoping Review

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Abstract. Healthcare systems in western countries are continuously working to achieve efficient resource allocation and to improve access to quality medical care. The implementation of standardised care processes promises better integration and coordination of care across several healthcare providers. In this context, an increasing use of the term patient pathway is recognised within official documents provided by health authorities and within scientific publications in recent years. However, a common understanding, distinguishing the term from other pathway approaches such as care- or clinical pathways, is missing. By means of a scoping review we analysed 132 publications in order to clarify key concepts and the understanding of patient pathways. Six common themes in the literature were identified and results show that individualisation and care continuity are essential descriptive characteristics. Using this motivation, we discuss the main implications for research and practice by the example of comprehensive cancer care in the European Union.

Keywords: patient pathways, care networks, scoping review

1 Introduction

Health care faces a broad spectrum of transition processes that necessitate integrated care delivery. In this context, demographic change, skilled worker shortage and an increasing number of patients with multimorbidity and chronic diseases are among the main drivers [1, 2]. For the latter, cancer is one of the most common and costly diseases in western countries [3, 4]. In order to coordinate cancer care on the national level and to increase access to quality cancer care, the implementation of Comprehensive Cancer Care Networks (CCCNs) is recommended by the European guide on quality improvement in comprehensive cancer control [5]. Such networks integrate different institutions and institutional units representing all relevant episodes for a patient's cancer care, i. e. research, prevention, diagnosis, treatment, follow-up, rehabilitation and end-of-life care [5]. One of the CCCNs' tasks is the provision of practical support tools. In this context, comprehensive, integrated patient pathways are recognised as a valuable approach [5]. Whereas the term patient pathway is often used with regard to

optimising cancer care processes and aligning information and communication flows, a common terminological basis is still missing. This has negative impact on the harmonisation of such big scale activities, in this case on EU level, and on the communication of their maturity in general. Hence, to further advance the utilisation of patient pathways in cancer care and beyond, clarification of the concept is necessary. It is still unclear whether patient pathways are any different from already well-established pathway approaches such as care pathways or clinical pathways. According to the definition used by the European Pathway Association, a “care pathway is a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period“ [6]. Clinical pathways particularly focus on the care provision within a single institution, e. g. a hospital [7].

The article aims to examine the literature body available on patient pathways. On this basis, key concepts of patient pathways shall be clarified and implications for future research and practice shall be discussed. Therefore, three research questions are to be answered: (RQ1) How has the literature on patient pathways developed over the years and which themes are addressed in the literature? (RQ2) What are characteristics of patient pathways including characteristics that differentiate them from other pathway approaches? (RQ3) What are potential implications for practice and future research? Accordingly, the article is structured as follows: The scoping review method used to address the research questions is described in section 2. The results are presented in section 3 by describing identified themes within the patient pathway literature. Also, common characteristics of patient pathways are derived within this section. The results of the review are discussed in the context of current literature and practice in section 4. This also includes the discussion of implications for research and practice as well as limitations of our study. A conclusion is given in section 5 by summarising the results and the contributions of the presented work.

2 Method

2.1 Scoping Review

In order to answer the research questions, a scoping review was conducted. Unlike a systematic literature review, a scoping review is a review type which is used to map key concepts underpinning a research area [8, 9]. A common purpose of scoping reviews is the identification of topics for future research [10]. They are often performed to determine and represent the body of literature and available evidence on a topic [8]. Since there is yet no comprehensive literature review about patient pathways available, the conduction of a scoping review is the appropriate choice to answer our research questions. Also, the research objectives are among those, that Anderson et al. (2008) state as the key criteria for which a scoping review is reasonable, e. g. clarification of the conceptual understanding of a topic where definitions are unclear and identification of research gaps advising on future research [10].

The conduction and reporting of the scoping review follows the guidelines proposed by Peters et al. [9]. The process of developing a review protocol as well as the literature search and selection process are not different from a systematic literature review, except

that there is no formal assessment of the methodological quality of the included literature [8, 9]. The developed review protocol included the definition of the search strategy, search terms, databases, screening approach, and the inclusion criteria.

In order to clarify the characteristics of the review, we draw on the established taxonomy for literature reviews described by Cooper [11] and define the focus, goal, perspective, coverage, organisation and audience as intended with the scoping review on patient pathways. The focus areas are outcomes, theories and applications. With respect to the research objective of this article, the goal of the review is twofold, i. e. it aims at the identification of central issues (see RQ1 and RQ2) as well as at the integration of existing literature (see RQ3). We take a neutral perspective in the presentation of the results and cover literature exhaustively with selected citations due to space limitations. The review is organised conceptually. The intended audiences are both scholars and practitioners in the fields of information systems and health care.

2.2 Search Strategy

The search strategy comprised a scientific database search and a google search in order to include both scientific articles and grey literature (e. g. government, business or institution reports regarding patient pathways) [12, 13]. The searches were carried out in April and May 2018. The search and review process is depicted in Figure 1.

During the screening phase, the exclusion criteria were non-scientific publication types (e. g. letters to the editors), the unavailability of an English abstract (reasonable for the results of the database search), or an extraneous topic (e. g. disease specific research aims that did not have patient pathways as a central topic). The high number of unavailable database records mostly results from unavailable poster abstracts. In such cases, the authors were contacted and asked to share their publication.

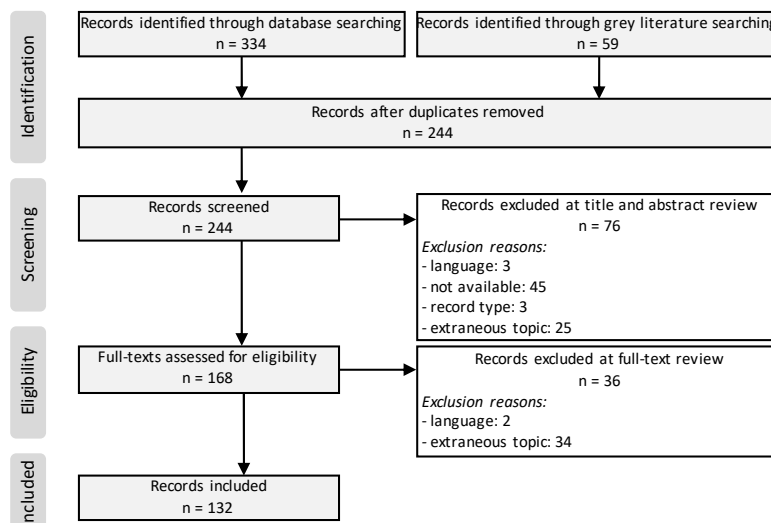


Figure 1. Scoping review process (representation mode based on [14])

During the full-text assessment, we did not restrict the analysis to full papers but also included abstracts, poster abstracts and posters, since one aim of the scoping review is the analysis of the currently available literature body on patient pathways. Included full-texts were in English or German, the latter occurring twice.

2.3 Database Search

We searched for "patient pathway" OR "patient pathways" in the titles of articles in PubMed, EbscoHost Academic Search Complete, Web of Science, and ScienceDirect. The decision to exclusively search for the term patient pathway is based on initial search term tests. These tests included potential synonyms such as clinical-, treatment-, care-, or integrated pathways and tested combinations with terms related to "definition" or "development". The searches resulted in a large amount of irrelevant articles and since the focus of the scoping review is the examination of the term patient pathway, we decided to exclusively search for this term.

The results were screened based on titles and abstracts by four reviewers. This procedure meets the requirement for at least two reviewers necessary for a scoping review [9]. In order to create a common understanding for the screening process a pre-test was conducted. Each reviewer analysed the first 15 included records regarding the context in which the term patient pathway was used. In a consensus meeting, the findings were discussed and the authors decided on a preliminary classification of research themes in the literature on patient pathways. This classification was assessed and refined in a second pre-test by applying it to the first 25 records of the included records and another consensus meeting. Based on this revised classification, the authors mapped all included records. During this, minor iterative refinements of the classification took place, leading to its final version as described in section 3.1.

2.4 Search for Grey Literature

We searched google exclusively for the singular and plural of the term patient pathway, for the same reasons as described for the database search. The first six results pages (the first 59 results, excluding hits to language translation pages) were screened by the authors. After that, there were scarcely any more relevant hits, which justifies ending the search at this point. The literature classification developed during the pre-test with the database search results was also applied to the included grey literature.

3 Results

3.1 Themes in the Patient Pathway Literature

As a first, theme-independent result, it can be stated that the interest in the examination of patient pathways in research and practice has increased over the years. This is shown by the increase in publications per year as depicted in Figure 2.

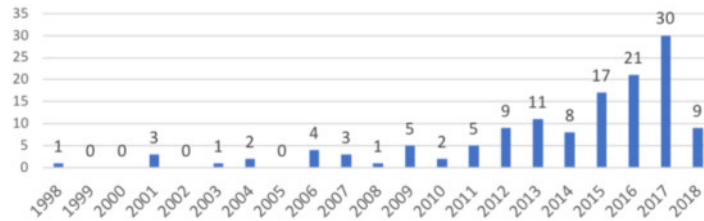


Figure 2. Number of publications per year (n = 132)

The literature can be roughly divided into publications examining patient pathways in general (n = 39) and publications addressing patient pathways for certain diseases (n = 93). For the latter, a major focus is on patient pathways in cancer care. As shown in Figure 3 (a), patient pathways for tuberculosis, heart diseases or alcoholism/drug addiction were examined much less frequently. The rest of the disease-specific literature was highly diverse. Thus, all diseases that were addressed only once or twice in the analysed patient pathway literature were summarised as others.

As described in section 2.3, during the analysis of the titles, abstracts and full-texts of the searched literature, a classification of six common research themes was developed and iteratively refined during the process. The identified themes regarding patient pathways are: definition and conceptualisation, development and implementation, analysis of patient pathways, responsibilities and roles, tool- and IT-support, and simulation. The frequency distribution of the themes is depicted in Figure 3 (b). Each theme is described in detail in the following.

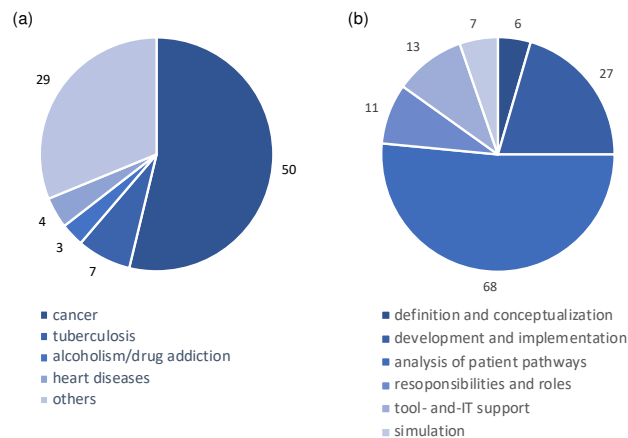


Figure 3. Results of the analyses: (a) focus of disease-specific patient pathway literature (n = 93), (b) themes in the patient pathway literature (n = 132)

Definition and Conceptualisation. Currently, there are only few articles (n = 6) examining characteristics or the notion of patient pathways. However, there is neither

a comprehensive analysis of the patient pathway approach nor a common definition available. Instead, the current literature discusses single important issues in relation to the patient pathway approach. For example, Berntsen and colleagues [15] qualitatively analysed the goals of care in individual patient pathways and concluded that the alignment of functional, biological and personal goals in a network of multidisciplinary care providers is essential to support care continuity. Another issue, addressed by Salamonsen et al. [16], is the influence of disruptive health and life events on the patient pathways. Also, they argue that patient pathways are beyond the known concept of clinical pathways, because they are not solely understood as the standardised, guideline-based provision of health care for certain patient types but also address multimorbidity and patient preferences [16]. Further basic characteristics of patient pathways can be taken from the patient pathway diagram as part of the NHS Data Model and Dictionary [17]. It describes the attributes and relationships to health care activities and organisations for the patient pathway class.

Development and Implementation. There are 27 publications that address the issues of development and implementation of patient pathways. We also included publications that present concrete patient pathways for certain diseases and health situations in this theme because they indicate how patient pathways are represented in practice. The concrete patient pathways analysed for the scoping review were represented as checklists [18], flowcharts [19] or non-standardised semi-formal process models often combined with textual descriptions [20, 21]. Standards, clinical practice guidelines or the results of systematic literature reviews are the starting points for pathway development and can be complemented by expert knowledge or experiences [22, 23]. Wicke et al. [24] propose a construction process for patient pathways based on a lifecycle consisting of four phases, i. e. preparation, construction and testing (main phase), implementation, and maintenance (controlling and revision). In the context of the latter, the collection of quality, service improvement and redesign tools could be used to improve certain stages of patient pathways [25]. So far, patient pathway development is rather addressed in the context of single health care institutions (e. g. a hospital [24]) than on network level.

The development and implementation are tasks of a multidisciplinary, inter-organisational team consisting of all key stakeholders along the patient pathway, e. g. involving hospital and community staff [23, 24, 26]. The development process should include consensus team meetings in order to reach agreement between all partners [27, 28]. A prominent example for nationally implemented patient pathways are the Danish Cancer Patient Pathways that were developed with a consensus seeking model ensuring the involvement and cooperation between bureaucrats, health professionals and politicians [29]. Besides the involvement of professional and administrative staff in the development process, the patient's perspective is highlighted as well. Focus group discussions are one way to identify patients' preferences and to integrate their input in the pathway development and maintenance phases [30].

Analysis of Patient Pathways. The analysis of patient pathways was subject to more than half of the publications analysed (n = 68). This theme can be further differentiated

into four sub-topics, which are (I) patient pathway analysis (n = 16), (II) the analysis of patient pathway usage (n = 27), (III) the analysis of patient pathway effects (n = 23), and (IV) the examination of data sources to be used for analysis purposes (n = 2). Patient pathway analysis (I) is an established phrase being used to describe the alignment between the care seeking patterns of patients with a certain disease and the availability of corresponding health care services [31, 32]. In this understanding, the patient pathway is not a predefined, standardised process but the actual, unplanned journey of a patient seeking health care services to address her/his health conditions. Based on this understanding, articles examining the pathways of patients before and after hospitalisation [33] or how patients decide where to seek care and what factors influence this decision [34] were also included in this sub-topic. In contrast, the analysis of the practical usage of patient pathways (II) is based upon predefined, standardised pathways. This sub-topic includes the analysis of patient characteristics for a certain patient pathway [35, 36], pathway compliance analyses [37], and process analyses (e. g. sources of delay [38, 39] or utilisation of certain activities in a pathway [40]). The analysis of patient pathway effects (III) comprises outcome studies, i.e. the analysis of the results after patient pathway implementation. Here, patient-related outcomes, such as survival and mortality, complications, quality of life and treatment-related side-effects [41, 42], and organisation-related outcomes, such as waiting times, length of hospital stay or timeliness of care [43, 44], are the focus. Another, rather minor sub-topic is the examination of data sources that can be used for analysis purposes (IV). In this context, the need for data linkage of electronic health records with clinical data registries as well as across regional borders is highlighted [45, 46]. This would increase the understanding of the complete patient pathway covering multiple involved care providers and also support national research.

Responsibilities and Roles. The responsibilities and roles of different stakeholder groups are discussed in 11 of the analysed articles. The role of nurses turned out be particularly important for patient navigation and early patient pathway optimisation, i.e. coordinating interventions, streamlining and planning the pathway, tailoring interventions to individual patient's needs and preferences [47–49]. The literature examines the relevance of nurses for patient management and for the provision of seamless care in both the acute care (clinical nurse specialists [47, 48]) and non-acute care setting (community nurses [49]). Other roles and their impact on patient pathways addressed in the literature are emergency care practitioners [50] and community pharmacists [51]. The important role of patients themselves is reflected with the patient-centred approach called user-led health care. It describes the systematic involvement of patients in the planning and execution of their individual treatment and care process and aligns patients' responsibilities with their preferences [52].

Tool- and IT-Support. Improving the utilisation and the streamlining of patient pathways by tools and information technology is a central issue for 13 of the analysed literature records. Here, patient education and patient empowerment by the online provision of information materials are typical applications. For example, there are internet-based, interactive patient pathways used as education tools for breast cancer

patients [53] or to explain a forthcoming surgical journey [54], and interactive, individualised online patient pathways with detailed, personalised timelines to keep patients informed and involved [55]. Another topic in relation to tool- and IT-support is the use of telemedicine in order to streamline a patient pathway, e. g. with early tele-assessment of stroke patients [56]. Furthermore, there are triage tools to assess and allocate patients to the appropriate pathway [57] and technical solutions for tracking patient pathways [58].

Simulation. The literature addressing simulation of patient pathways (n = 7) applies it for example to predict their outcomes. Simulation models are used to produce quantified output of patients with a certain diagnosis [59] or to simulate scenarios at the population level in order to support intervention planning of public health care [60]. Furthermore, simulation is used for teaching and training purposes, e. g. by fully simulating a hospital across the entire patient pathway in order to train expert health care providers [61] or by simulating the surgical patient pathway for undergraduate students to supplement classroom medicine and clinical practice [62].

3.2 Characteristics of patient pathways

The scoping review results show that currently a common definition of patient pathways is not available. However, characteristics of this approach can be identified from the included literature by analysing their understanding of patient pathways. It was found that there are related pathway terms also used as synonyms for patient pathways. Mainly, these are care pathways [47, 49, 63–65], treatment pathways [47, 66, 67], and patient journeys [45, 68, 69]. However, the usage of these terms was not reasoned in the articles. The full-texts of the included literature were screened for statements describing characteristics of patient pathways, such as:

“[...] ‘patient pathways’ from a patient perspective, understood as incorporated into socioculturally constructed life courses. [...] Not only ‘health events’, but also ‘life events’ are included in our understanding of patient pathways.” [16]

“Based on treatment guidelines, patient pathways display an optimal sequence of staff actions in the preoperative, operative, and postoperative in- and outpatient treatment.” [24]

“Patient pathways are tools that assist in providing general guidelines of care for dealing with individuals and groups of patients suffering from a wide variety of diseases.” [70]

Based on the analysis of such statements and the identified themes in the literature, descriptive characteristics of patient pathways can be summarised as follows. Patient pathways are:

- stating and aligning functional, biological, and patient-related goals of care [15, 16],
- focusing on patient group and individual patient planning and -management for complex long-term conditions [16, 70–72],
- describing and sequencing key components of care to guide care provision and the patient journey [18–21, 23, 24],

- comprising the whole route a patient takes including inpatient and outpatient settings and thus, are typically inter-organisational pathways [45, 68, 71, 73] but individual stakeholders can focus on single episodes (e. g. surgery or hospital stay) [24]
- developed, implemented and used by a multidisciplinary care team consisting of professional and informal caregivers and involving the patient [23, 24, 26, 30, 52],
- evidence-based (medical guidelines, standards) and experts' experiences [22, 23],
- used for patient information, documentation, monitoring and evaluation purposes (e. g. assessment of quality and efficiency of care delivery or patient-related outcome measures) [37–44, 53, 55, 74].

4 Discussion

As the analysis revealed, more than half of the reviewed publications are related to oncological diseases. This emphasises the initial statement that patient pathways are recognised as a valuable approach in cancer care in order to create seamless care, inform the patient, plan the care process, and implement medical guidelines [5]. The results of the scoping review also show that the majority of publications addresses the analysis of various aspects related to patient pathways such as the effects of their application or their usage (see Figure 3 (b)). Still, the broad use of the term indicates some ambiguity in its understanding. Surprisingly, there are a lot of papers analysing effects of patient pathways but without referring to a common definition of this concept.

Although some papers discuss the use of patient pathway in an intra-organisational context and other focus on the inter-organisational setting, the proposed characteristics cover both aspects because patient pathways within a single institution are also embedded in the inter-organisational route of a patient. Interfaces and the relation to the overall process have to be described accordingly. Furthermore, ambiguity exists regarding the time perspective of patient pathways. Some authors focus more on the general journey of patients through the health care delivery system, analysed retrospectively for example by means of patient pathway analysis. Others rather focus on prospectively defined pathways for a patient (group) to guide the provision of care. The latter highlights the planning character of a pathway, which is also the aim of related pathway approaches such as clinical pathways and care pathways.

In the context of existing literature on other pathway approaches, patient pathways comprise the core concept of care pathways, that are already well established in the field of medical process management nowadays [75, 76]. However, patient pathways have a stronger focus on the individual patient. This is particularly apparent in form of aligning the goals of care to a patient's needs and preferences and, accordingly, tailoring the pathway to the individual. The concept of patient pathways emphasises the care process from the perspective of the patient and also includes mechanisms of empowerment and engagement. Based on the identified characteristics, patient pathways are also not equivalent to clinical pathways [7] because these typically do not cover the whole care chain across in- and outpatient settings.

The current state of literature provides several action points for future research. A consensus regarding the patient pathway understanding should be developed, e. g. by

an expert panel discussing and rating the identified characteristics. From a practical perspective, a stronger methodological support for developing and implementing patient pathways is desirable. This could be achieved by providing a tool for the preparation of patient pathways, their adaption to patient-individual characteristics and to local specifics of the application environment. Latest research, e. g. on adaptive and personalised pathways [77] or on multi-perspective pathway modelling languages [78], can be exploited for this purpose. The mechanisms of reference modelling [79] might provide appropriate means to combine generic templates with intended governance for health process design. Taking up the example of comprehensive cancer care, a method for patient pathway development could allow CCCNs to prepare common templates of patient pathways for specific tumour entities. These could for example specify the main goals, phases and milestones of care for a specific patient type as well as roles and tasks within the care network. Such a template, functioning as a reference model, could then be adapted to regional conditions and patient individualities based on adaption guidelines provided along with the method. In order to increase usability, the specification of user requirements is essential, since the users have an application-oriented background being e. g. physicians, nurses or a cancer patient. In perspective, this approach could increase comparability and set process-oriented quality standards for cancer care in CCCNs. This could contribute to developing more process-oriented measures for quality and performance assessment. Thereby, insights for continuous patient pathway improvement could be gained.

Critically reflecting on the methodological approach of the presented paper, the scoping review could be broadened by expanding the database search to titles and abstracts and by adding forward and backward searches. The mapping of the literature could be enriched by a multi-disciplinary review team [10] that also involves scholars from the health care domain. Due to the nature of the scoping review it does not include a process of quality assessment of the literature and thus, has some limitations [8]. For this reason, recommendations for practice are preliminary and the understanding of patient pathways could be further examined by a systematic literature review. The conducted scoping review determined the high value and scope of such.

5 Conclusion

The article aimed at examining the current literature body available on patient pathways in order to clarify key characteristics of this approach and to discuss implications for research and practice. A systematic scoping review was conducted. It included a database and a grey literature search. An increase in the discussion of the concept in the literature was confirmed. There were six common themes identified in the current literature on patient pathways. These are definition and conceptualisation, development and implementation, analysis of patient pathways, responsibilities and roles, tool- and IT-support, and simulation. The majority of publications addresses analytical topics, such as the analysis of patient pathway usage or effects but a common definition is currently not available. However, there are typical characteristics of patient pathways that were summarised based on the reviewed literature. Patient pathways differ from

other pathway approaches as they rather aim at planning care for multimorbid patients with complex health conditions. They focus on the inter-organisational setting and patients' needs and preferences. We also discussed potential implications for practice and research. Particularly, the methodological and technological support for developing and implementing patient pathways should be improved.

The presented work contributes to the knowledge base by consolidating the understanding of patient pathways and by summarising typical characteristics. As we pointed out, the patient pathway approach builds upon the core concept of care pathways. Since there are concerns regarding the feasibility of care pathways for complex health conditions that require integrated care, we see the opportunity that patient pathways drive a transition to a broader utilisation of pathways for chronic and complex health conditions such as cancer. In summary, our work informs the debate on patient pathways and is a starting point for future research and practical applications.

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