Patient-centered care pathways: what does it mean? An integrative conceptual framework to meet the need of an international consensus: a qualitative systematic review protocol

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ABSTRACT

Background: Faced with increased expectations regarding the quality and safety of health care delivery systems, a number of stakeholders are increasingly looking for more qualitative and efficient ways to deliver care. This study is conducted to provide a clear definition of the patient-centered care pathway and its characteristics to meet the need for an international consensus.

Methods: This qualitative systematic review aims to perform a systematic synthesis of published evidence concerning (1) the definition of the patient trajectory, patient pathway or patient journey and (2) their characteristics. With a consulting librarian, a comprehensive and systematic search in three databases was conducted (PUBMED, Embase, ABI/Inform), from 1995 to 2020 without language criteria. Eligibility criteria guiding data selection will follow the PICO mnemonic criteria consisting of (1) Population : all types of patients managed by health care delivery systems for an acute or chronic condition regardless of age or condition, (2) Phenomena : studies that contribute to the definition and conceptualization of the concepts of care trajectory, care pathway and patient journey resulting in a theoretical and conceptual contribution, and (3) Context : health care providers include all providers of primary, secondary, tertiary, and quaternary care in any geographic area. Two reviewers will independently screen, select, extract data and make a critical assessment of the methodology used with the JBI Qualitative Assessment and Review Instrument (JBI QARI).

Discussion: This systematic review will provide much-needed knowledge regarding patient-centered pathways. The results will benefit clinicians, decision makers, and researchers by giving them a clear and integrated definition and understanding of the patient-centered care pathways and their characteristics to finally meet the need for an international consensus.

Systematic review registration number:

Keywords: Patient pathway, Patient trajectory, Patient journey, Patient-centered, Patient experience, Qualitative systematic review.

REVIEW QUESTION

What is the difference in terms of definition and characteristics between the concepts of care pathway, care trajectory and patient journey?

In light of these results, how can we redefine and characterize the patient-centered care pathway focused on the patient's needs and expectations to meet the need of an international consensus?

INTRODUCTION

Providing health and wellness services from an efficiency, equity, and sustainability perspective may pose major challenges in the near future, given the advent of new technologies and the emergence of other disruptive changes¹, including accountability for quality delivery and cost control. Indeed, in its book "Crossing the Quality Chasm: A New Health System for the 21st Century,"² the U.S. Institute of Medicine (IOM) highlighted in 2001 the problem of poor quality in health care delivery systems and issued an urgent call for fundamental changes in the organization and delivery of health care. This analysis of a "quality chasm" was based on four findings: the increasing complexity of science and technology, the rise of chronic disease, a poorly organized health care system, and constraints in harnessing the information technology revolution. Twenty years later, these challenges are still pervasive. The existence of key problems in the approach to quality delivery persist³. These problems are related as much to the significant fragmentation of organizations^{2,4,5}, as they are between business units within clinical organizations themselves⁴. This results in siloed work with each provider entity responsible for only a portion of the overall quality and complete patient experience of care⁴. This operational reality is reflected in the approach of quality and performance management programs that focus primarily on the perspective and needs of healthcare professionals and organizations rather than on the needs and expectations of patients at the systemic level. This approach, focused on the perspective of professionals, leads to inconsistencies in patient care resulting in problems of quality and accessibility for the patient, as well as additional costs for society.

The systemic approach through a care pathway program seems to be a relevant solution. Proposed since the end of the 1990s, this approach has given rise to a significant amount of terminology. Thus, the terms integrated care pathway, care trajectory, patient journey, care continuum have been used even though they often cover identical realities⁶. Moreover, this approach has given rise to a very large number of definitions, up to 37 definitions being found⁷. Given this plurality of definitions, the characteristics of patient-centered care pathways have also been subject to great variability⁷. The definition and characteristics of the trajectory varies from country to country and may include only one episode of care, focus only on the treatment phase, include only the post-diagnosis phase or encompass the entire patient journey. For example, in oncology, most pathways were limited to specific components of the cancer journey⁸. As a result, a systematic review of cost-effectiveness of colorectal cancer highlighted obvious discrepancies in the results of studies from different regions. They attribute these inconsistencies to several factors including the difference in the description of the trajectory and the variability in treatment phases used in the studies⁹. This variability results in an inability to conduct reliable comparative studies of care pathway programs at the international level. For this reason, in 2020 the WHO called the "ministries of health to design optimal care pathways, mapping patient's journey from first contact with the health system to completion of treatment and survivor care..."¹⁰. This definition is all the more necessary as certain barriers to the implementation of these programs have been removed. On the one hand, limited access to valid and reliable data from

multiple organizations¹¹ has been offset by massive investment of health systems in Electronic Medical Records which has provided structured and interconnectable data to examine the patient's trajectory through the system in an innovative way¹². On the other hand, the main difficulties in highlighting the complexity of the referral trajectory¹³, frequently resulting from the mobilization of a Delphi method mobilizing the clinicians' perspective, have been overcome by proposing new methods such as machine learning or qualitative methods, these methods focusing on the real care trajectory and for the qualitative part on the patient's experience^{14,15,16} through their needs and expectations. That's why it is now time to define a standardized and internationally recognized integrative conceptual framework in order to meet the need for sharing knowledge internationally regarding the development, implementation and evaluation of pathways⁷.

A preliminary search for existing systematic reviews on the topic has been conducted in JBI Database of Systematic Reviews and Implementation Reports, Cochrane Database and PROSPERO. Patient pathways have already been the subject of few systematic reviews, but authors limited their search to use and outcomes for specific pathologies such as cancer in general¹⁷, breast cancer¹⁸, blunt thoracic injury¹⁹, cardiovascular disease²⁰, adolescent idiopathic scoliosis²¹ or for specific phases such as end of life²². To our knowledge, the only review that deals with the concept of care pathways in a whole-of-system approach and not focused on one pathology was made in 2006²³, reviewed literature published within a short, 3-year time period and used only one bibliographic database (PubMed).

The patient-centered care pathway programs have recently demonstrated encouraging results in terms of reduced variation in care, improved accessibility, quality, sustainability, and cost-effectiveness of care⁷. Furthermore, the evolution of knowledge and information technology and the investment of health systems in data-sharing infrastructures, as well as a definition of the levers of patient engagement, make it possible to define a powerful model for improving care trajectories. Therefore, our systematic review of the literature aims to answer the following research questions: What is the difference in terms of definition and characteristics between a care pathway, a care trajectory and a patient journey? In light of these results, how can we redefine and characterize the patient-centered care pathway focused on the patient's needs and expectations to meet the need of an international consensus?

REVIEW QUESTIONS

What is the difference in terms of definition and characteristics between a care pathway, a care trajectory and a patient journey?

In light of these results, how can we redefine and characterize the patient-centered care pathway focused on the patient's needs and expectations to meet the need of an international consensus?

INCLUSION CRITERIA

As recommended by JBI Reviewer's Manual²⁴, this review follows the PICO mnemonic criteria²⁵ consisting in defining both the Population, the Phenomena of Interest and the Context.

Population

This review considers qualitative studies and conceptual articles that include or focus on all types of patients managed by health care delivery systems for an acute or chronic condition regardless of age or condition.

Phenomena of interest

This review focuses on studies that contribute to the definition and conceptualization of the concepts of patient trajectory, patient pathway or patient journey resulting in a theoretical and conceptual contribution. Thus, on the one hand, qualitative studies involving a single episode of care limited in time (a one-time treatment) or space (a single hospital service/department) were excluded to the extent that the care trajectory involves multiple points of interaction over time^{26,27} and multiple organizational structures or intra-organizational entities along the care continuum²⁸. On the other hand, studies with no theoretical or conceptual input were also excluded.

Context

The context studied is composed of health care providers in any geographic area. Health care providers include all providers of primary, secondary, tertiary, and quaternary care²⁸. These providers can be both health care organizations (general practice clinics, hospitals, intensive care units, emergency departments, long-term care facilities, etc.) and individual providers (physicians, nurses, administrators, pharmacists, etc.).

Types of studies

This review considers conceptual articles or qualitative studies that focus on qualitative data including, but not limited to, designs such as phenomenology, grounded theory, ethnography, and action research. Descriptive qualitative studies that describe the experience or describe the effects of the experience were also considered. Mixed-methods studies were considered only if data from the qualitative components could be clearly extracted. Our search focused on peer-reviewed scientific articles. Therefore, books, doctoral or master's theses, and abstracts from conference presentations were excluded due to time and resource limitations. No language limits were applied. Finally, the study period was limited to the years 1995 to 2020, as the concept of the care pathway program was implemented in the second half of the 1990s⁶ and in line with the objective of achieving a current redefinition and characterization of the patient-centered care pathway.

SEARCH STRATEGY

The search strategy was developed in collaboration with a consulting librarian and aims to find published peer-reviewed studies. An initial limited search of MEDLINE and CINAHL has been undertaken followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. This informed the development of a search strategy which was tailored for each information source. The full search strategy in PUBMED, Embase and ABI/Inform are detailed in **Appendix 1**. The interrogation of the three databases resulted in 15281 studies. These studies were imported into the Covidence® software and 209 duplicates were automatically deleted. The reference list of all studies selected for critical appraisal will be screened for additional studies.

ASSESSMENT OF METHODOLOGICAL QUALITY

Following the standardized critical appraisal instruments from the JBI Qualitative Assessment and Review Instrument (JBI QARI)²⁴, eligible studies will be assessed by two independent reviewers for methodological validity prior to inclusion in the review. Authors of papers will be contacted to request missing or additional data for clarification, where required. Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer. The results of critical appraisal will be reported in narrative form, regardless of studies methodological quality, and data extraction and synthesis will be summarized in a **Table**.

DATA EXTRACTION

Qualitative data will be extracted from papers included in the review using the standardized data extraction tool from JBI SUMARI by two independent reviewers. The data extracted will include specific details about the populations, context, culture, geographical location, study methods and the phenomena of interest relevant to the review question and specific objectives. Findings, and their illustrations, will be extracted and assigned a level of credibility.

DATA SYNTHESIS

Qualitative research findings will, where possible be pooled using JBI SUMARI with the meta aggregation approach. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence based practice. Where textual pooling is not possible the findings will be presented in narrative form.

CONFLICTS OF INTEREST

The authors declare no conflict of interest

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APPENDIX

Appendix I: Search strategy

PubMed

Date of the search: 16-01-2021

Database limit: No database limit has been apply

Concepts	#	Search strategy	Results
Healthcare pathway (Controlled vocabulary)	1	"Patient Care Management"[Mesh:NoExp] OR "Workflow"[Mesh:NoExp]	10,098
Healthcare pathway (Free vocabulary)	2	Healthcare pathway*[TIAB] OR Clinical Processes[TIAB] OR medical processes[TIAB] OR healthcare processes[TIAB] OR Patient Journey[TIAB] OR processes model*[TIAB] OR workflow management[TIAB]	2,309
Healthcare pathway (Combined)	3	#1 OR #2	12,270
Healthcare access (Controlled vocabulary)	4	"Health Services Accessibility"[Mesh:NoExp] OR "Health Equity"[Mesh] OR "Waiting Lists"[Mesh:NoExp] OR "Time Factors"[Mesh:NoExp]	1,280,419
Healthcare access (Free vocabulary)	5	Health Services Access*[TIAB] OR Health Care Access*[TIAB] OR Health Services Availab*[TIAB] OR Access to Health Care[TIAB] OR Health Equity[TIAB] OR Health inequit*[TIAB] OR Health disparities[TIAB] OR Wait* times[TIAB] OR Waiting Lists[TIAB]	38,478
Healthcare access (combined)	6	#4 OR #5	1,307,321
Effectiveness (Controlled vocabulary)	7	"Patient Satisfaction"[Mesh:NoExp] OR "Patient Readmission"[Mesh] OR "Hospital Mortality"[Mesh]	140,733
Effectiveness (Free vocabulary)	8	Patient Satisfaction[TIAB] OR Patient needs[TIAB] OR Hospital Readmissions[TIAB] OR Patient Readmission[TIAB] OR 30 Day Readmission[TIAB] OR readmission rate[TIAB] OR Mortalit*[TIAB] OR Death rate[TIAB]	854,571
Effectiveness (combined)	9	#7 OR #8	936,302
Efficiency as productivity (Controlled vocabulary)	10	"Operative Time"[Mesh] OR "Office Visits/statistics and numerical data"[Mesh:NoExp] OR "Referral and Consultation/statistics and numerical data"[Mesh:NoExp] OR "Bed Occupancy"[Mesh:NoExp] OR "Time-to-Treatment"[Mesh] OR "Time Management"[Mesh:NoExp]	41,453
Efficiency as productivity (Free vocabulary)	11	Surgical Time*[TIAB] OR Operative Time*[TIAB] OR "Bed Occupancy"[TIAB] OR Treatment Delay*[TIAB] OR Time-to-Treatment*[TIAB] OR Delayed Treatment*[TIAB] OR length of operation[TIAB] OR length of surgery[TIAB] OR operat* time [TIAB] OR surgery time[TIAB] OR surgery duration[TIAB] OR patient referral[TIAB] OR therapy Delay*[TIAB]	38,259
Efficiency as productivity (combined)	12	#10 OR #11	72,736

Efficiency as economic (Controlled vocabulary)	13	"Costs and Cost Analysis"[Mesh:NoExp] OR "Cost-Benefit Analysis"[Mesh] OR "Health Care Costs"[Mesh] OR "Direct Service Costs"[Mesh] OR "Cost Control"[Mesh] OR "Hospital Costs"[Mesh]	201,783
Efficiency as economic (Free vocabulary)	14	Cost*[TIAB]	640,920
Efficiency as economic (combined)	15	#13 OR #14	716,284
Safety and quality (Controlled vocabulary)	16	"Quality Assurance, Health Care"[Mesh:NoExp] OR "Quality of Health Care"[Mesh:NoExp] OR "Total Quality Management"[Mesh:NoExp] OR "Quality Indicators, Health Care"[Mesh:NoExp] OR "Efficiency, Organizational"[Mesh] OR "Medical Errors"[Mesh:NoExp] OR "Medication Errors"[Mesh:NoExp] OR "Accidents, Occupational"[Mesh]	210,821
Safety and quality (Free vocabulary)	17	Quality of Healthcare[TIAB] OR Healthcare Quality[TIAB] OR Continuous Quality Management[TIAB] OR Total Quality Management[TIAB] OR Six Sigma*[TIAB] OR hospital accidents[TIAB] OR medical error[TIAB] OR diagnostic error[TIAB] OR medication error[TIAB] OR surgical error[TIAB] OR therapeutic error[TIAB]	10,963
Safety and quality (combined)	18	#16 OR #17	216,480
Characteristics of Staff (Controlled vocabulary)	19	"Job Satisfaction"[Mesh:NoExp] OR Personnel Turnover[Mesh:NoExp] OR Personnel Loyalty[Mesh:NoExp] OR "Workload"[Mesh] OR Absenteeism[Mesh:NoExp] OR Presenteeism[Mesh:NoExp] OR "Shift Work Schedule"[Mesh]	57,673
Characteristics of Staff (Free vocabulary)	20	Job satisfaction[TIAB] OR work satisfaction[TIAB] OR physician* satisfaction[TIAB] OR nurs* satisfaction[TIAB] OR allied health* satisfaction[TIAB] OR staff Loyalty[TIAB] OR staff turnover[TIAB] OR staff rentention[TIAB] OR Personnel Turnover[TIAB] OR Personnel rentention[TIAB] OR Personnel Loyalty[TIAB] OR employee rentention[TIAB] OR employee turnover[TIAB] OR employee Loyalty[TIAB] OR Absenteeism[TIAB] OR Presenteeism[TIAB] OR Night Shift[TIAB] OR Rotating Shift[TIAB] OR overtime[TIAB] OR workload[TIAB]	80,766
Characteristics of Staff (combined)	21	#19 OR #20	120,061
Combination of concepts	22	#3 AND (#6 OR #9 OR #12 OR #15 OR #18 OR #21)	4,243

Embase (Embase.com)

Date of the search: 16-01-2021

Database limit: Embase results only

Concepts	#	Search strategy	Results
Healthcare pathway (Controlled vocabulary)	1	'health care management'/de OR 'managed care organization'/de	31,359

Healthcare pathway (Free vocabulary)	2	"workflow management":ti,ab,kw OR "Healthcare pathway\$:ti,ab,kw OR "Patient Journey":ti,ab,kw OR ((Clinical OR medical OR Healthcare OR model*) NEAR/3 processes):ti,ab,kw	14,930
Healthcare pathway (Combined)	3	#1 OR #2	46,157
Healthcare access (Controlled vocabulary)	4	'health care access'/de OR 'health equity'/de OR 'time factor'/de OR 'hospital admission'/de	307,606
Healthcare access (Free vocabulary)	5	(Health NEAR/2 (Access* OR Availab* OR Equity OR inequit* OR disparities)):ti,ab,kw OR "Wait* times":ti,ab,kw OR "Waiting Lists":ti,ab,kw	67,971
Healthcare access (combined)	6	#4 OR #5	360,685
Effectiveness (Controlled vocabulary)	7	'patient satisfaction'/de OR 'hospital mortality'/de OR 'hospital readmission'/de	239,961
Effectiveness (Free vocabulary)	8	(Patient NEAR/2 (satisfaction OR needs)):ti,ab,kw OR Mortalit*:ti,ab,kw OR "Death rate":ti,ab,kw OR ((Hospital OR Patient OR "30 Day" OR rate) NEAR/2 readmission\$):ti,ab,kw	1,268,791
Effectiveness (combined)	9	#7 OR #8	1,395,359
Efficiency as productivity (Controlled vocabulary)	10	'operation duration'/de OR 'hospital bed utilization'/de OR 'time to treatment'/de OR 'time management'/de OR 'consultation'/de OR 'patient referral'/de OR 'therapy delay'/de	374,406
Efficiency as productivity (Free vocabulary)	11	((operat* OR surgery OR surgical) NEAR/2 (time\$ OR duration OR length)):ti,ab,kw OR "Bed Occupancy":ti,ab,kw OR "Time-to-Treatment":ti,ab,kw OR "patient referral":ti,ab,kw OR ((Treatment\$ OR therapy) NEAR/2 Delay*):ti,ab,kw	211,150
Efficiency as productivity (combined)	12	#10 OR #11	497,452
Efficiency as economic (Controlled vocabulary)	13	'cost'/de OR 'health care cost'/de OR 'hospital cost'/exp OR 'cost control'/de OR 'cost benefit analysis'/de OR 'cost effectiveness analysis'/de	509,663
Efficiency as economic (Free vocabulary)	14	Cost*:ti,ab,kw	871,016
Efficiency as economic (combined)	15	#13 OR #14	1,090,146
Safety and quality (Controlled vocabulary)	16	'health care quality'/de OR 'medical error'/exp OR 'total quality management'/de OR 'organization and management'/de OR 'productivity'/de OR 'occupational accident'/de	868,721

Safety and quality (Free vocabulary)	17	((medical OR diagnostic OR therapeutic OR medication OR surgical) NEAR/2 error):ti,ab,kw OR (Quality NEAR/2 Healthcare):ti,ab,kw OR ((Continuous OR total) NEAR/2 ("Quality Management")):ti,ab,kw OR "hospital accidents":ti,ab,kw OR "Six Sigma\$":ti,ab,kw	19,013
Safety and quality (combined)	18	#16 OR #17	875,097
Characteristics of Staff (Controlled vocabulary)	19	'job satisfaction'/de OR 'personnel management'/de OR 'absenteeism'/de OR 'presenteeism'/de OR 'shift work'/exp OR 'working time'/de OR 'workload'/de	152,737
Characteristics of Staff (Free vocabulary)	20	((Job OR Work OR physician\$ OR nurs* OR "allied health\$") NEAR/2 satisfaction):ti,ab,kw OR ((staff OR Personnel OR employee) NEAR/2 (Loyalty OR turnover OR retention)):ti,ab,kw OR ((Night OR Rotating) NEAR/2 Shift):ti,ab,kw OR Absenteeism:ti,ab,kw OR Presenteeism:ti,ab,kw OR overtime:ti,ab,kw OR workload:ti,ab,kw	73,538
Characteristics of Staff (combined)	21	#19 OR #20	184,168
Combination of concepts	22	#3 AND (#6 OR #9 OR #12 OR #15 OR #18 OR #21)	20,144
Embase results only	23	#22 AND [embase]/lim NOT ([embase]/lim AND [medline]/lim)	7,111

ABI/Inform

Date of the search: 16-01-2021

Database limit: Limit results to academic publications

Concepts	#	Search strategy	Results
Healthcare pathway (Controlled vocabulary)	1	SU("Patient care planning")	465
Healthcare pathway (Free vocabulary)	2	TI,AB("workflow management" OR "Healthcare pathway?" OR "Patient Journey") OR TI,AB((Clinical OR medical OR Healthcare OR model*) NEAR/3 processes)	25 444
Healthcare pathway (Combined)	3	1 OR 2	25 897
Healthcare access (Controlled vocabulary)	4	SU("Health care access" OR "Medical waiting lists")	4 743
Healthcare access (Free vocabulary)	5	TI,AB((Health OR "Health Care") NEAR/2 (Access* OR Availab*)) OR TI,AB(Health NEAR/2 (Equity OR inequit* OR disparities)) OR TI,AB("Wait* times" OR "Waiting Lists")	14 194
Healthcare access (combined)	6	4 OR 5	17 590
Effectiveness (Controlled vocabulary)	7	SU(Mortality OR "Patient Satisfaction")	21 608

Effectiveness (Free vocabulary)	8	TI,AB(Patient NEAR/2 (satisfaction OR needs)) OR TI,AB((Hospital OR Patient OR "30 Day" OR rate) NEAR/2 readmission\$) OR TI,AB(Mortalit* OR "Death rate")	33 009
Effectiveness (combined)	9	7 OR 8	43 291
Efficiency as productivity (Controlled vocabulary)	10	SU("Time management" OR "Medical referrals")	5 798
Efficiency as productivity (Free vocabulary)	11	TI,AB((operat* OR surgery OR surgical) NEAR/2 (time? OR duration OR length)) OR TI,AB((Treatment? OR therapy) NEAR/2 Delay*) OR TI,AB("Bed Occupancy" OR "Time-to-Treatment" OR "patient referral")	8 704
Efficiency as productivity (combined)	12	10 OR 11	14 465
Efficiency as economic (Controlled vocabulary)	13	SU(Costs OR "Benefit cost analysis" OR "Cost analysis" OR "Health care expenditures" OR "Hospital costs" OR "Cost control")	489 564
Efficiency as economic (Free vocabulary)	14	TI,AB(Cost*)	1 062 839
Efficiency as economic (combined)	15	13 OR 14	1 308 330
Safety and quality (Controlled vocabulary)	16	SU("Quality control" OR "Quality of care" OR "Total quality" OR Efficiency OR "Medical errors" OR "Occupational accidents")	162 388
Safety and quality (Free vocabulary)	17	TI,AB((medical OR diagnostic OR therapeutic OR medication OR surgical) NEAR/2 error) OR TI,AB(Quality NEAR/2 Healthcare) OR TI,AB((Continuous OR total) NEAR/2 ("Quality Management")) OR TI,AB("hospital accidents" OR "Six Sigma\$")	15 577
Safety and quality (combined)	18	16 OR 17	168 035
Characteristics of Staff (Controlled vocabulary)	19	SU("Job satisfaction" OR "Employee turnover" OR Workloads OR Absenteeism OR "Shift work" OR Overtime)	45 347
Characteristics of Staff (Free vocabulary)	20	TI,AB((Job OR Work OR physician? OR nurs* OR "allied health?") NEAR/2 satisfaction) OR TI,AB((staff OR Personnel OR employee) NEAR/2 (Loyalty OR turnover OR rentention)) OR TI,AB((Night OR Rotating) NEAR/2 Shift) OR TI,AB(Absenteeism OR Presenteeism OR overtime OR workload)	48 335
Characteristics of Staff (combined)	21	19 OR 20	72 938
Combination of concepts	22	3 AND (6 OR 9 OR 12 OR 15 OR 18 OR 21)	5 633

Limit results to academic publications	23	n/a	3 927
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