TITLE PAGE

RUNNING HEAD: Person-centered rehabilitation literature

TITLE: Scoping review of the person-centered literature in adult physical rehabilitation

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BODY OF THE MANUSCRIPT

TITLE: Scoping review of the person-centered literature in adult physical rehabilitation

ABSTRACT

Objective: To map the literature pertaining to adult Person-Centered Rehabilitation (PCR).

Data Sources: Following our previously published scoping review protocol, data were identified through: three major databases, snowball searches and expert consultation.

Study Selection: Two independent reviewers identified English-language papers which addressed adult physical rehabilitation and met one or more of the six pre-defined inclusion categories for PCR content.

Data Extraction: Two independent reviewers extracted key characteristics of included papers (e.g. aims, methods, participants). Quantitative methods (descriptive statistics, regression analysis) and qualitative content analyses were used to synthesize the results.

Data synthesis: Of 5084 unique records initially screened, 145 papers were included: 111 empirical, including 11 systematic reviews. Empirical papers had data from 13498 clients and 3849 providers, in total. Yearly publications grew exponentially from 2000 to 2017 (r^2= 0.65; $p<0.01$). Publications were unevenly distributed by countries (e.g. United States' publications per population size was 45 times lower than New Zealand's). Most papers focused in more

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than one profession, setting-type or health conditions, respectively 57.2%, 66.2%, and 60.7%. Finally, more than half of the empirical papers (53.2%) studied implementation of PCR approaches, including its effect.

Conclusion: This scoping review synthesizes key characteristics and publication trends in the PCR literature, which is mainly empirical and growing exponentially over time. Stakeholders can use the identified trends, gaps, and literature map to guide further PCR research, and both clinical and organizational practices. The high prevalence of papers focused on multiple professions, settings-type, or health conditions reinforces the need for developing a transdisciplinary, trans-service model of PCR, which will be derived from a thematic analysis of this body of literature.

Keywords:

Rehabilitation; Review; Patient-Centered Care

Abbreviations:

PCR: Person-Centered Rehabilitation;

PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Extension for Scoping Reviews.

OT: Occupational Therapy

PT: Physical Therapy

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INTRODUCTION

The terms patient- or person-centered are often used to describe healthcare and rehabilitation [1-5]. However, what these terms mean in practice is problematic [5-11]. In the broader healthcare, the concept of patient-centeredness has been defined, broadly, as the ability to meet a person's needs, values or preferences, optimizing the person's experiences with care, and fully involving the patients and their perspectives into care [2,5,10,12-14]. More than circumscribed activities, such as providing information to people or involving them into decision-making, the concept of person-centered has been framed as a philosophy of practice, a means of thinking and doing care *with the person* rather than *for patients* [7,10,14-17].

The term "person-centered" has been, therefore, increasingly preferred over "patient-centered", since it reflects the humane and contextual factors of the *person* beyond the biological factors of the *patient* [5,11,17]. Apart from nuances, different terms (e.g. patient-centered, person-centered, client-centered) are often used interchangeably to largely convey the same core principles [11,13,15,18]: a tailored approach that is based on respectful, compassionate, caring, trustful, curious, attentive, and supportive relationships [10,11,13,16], backed by an organization of health-services that optimizes the patient experience, inclusively across providers [2,5,12,13,17-20].

Conceptual blurring occurs nonetheless; and that results in important differences in the way broad PC principles are translated into healthcare practices [10,21]. It is not surprising, therefore, to find that person-centered approaches are being framed, implemented, and finally measured in many different ways within the healthcare field [5,9,10,17,21,22], and have either positive or deleterious effects as a result [23,24].

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In that context, systematic efforts have been made to map and synthesize the broad healthcare literature on the concept of person-centeredness, including to identify which specific components it should entail [7,11,21,25-28]. While the person-centered philosophy has been strongly recommended for rehabilitation [15,29-34], and even argued to be an intrinsic part of it, [4,29,34] the field is absent of systematic endeavors mapping and synthesizing how person-centeredness has been addressed in the rehabilitation literature.

This lack of knowledge synthesis within the rehabilitation field has two major consequences. First, the field remains unaware of how the literature has been approaching Person-Centered Rehabilitation (PCR) topics, e.g. in terms of (evolving) volume, subjects addressed, and methods used. The identification of currents trends and gaps is likely important to guide further developments [35,36]. Second, it is unknown how PCR has been conceptualized and operationalized by the rehabilitation literature, i.e. what does the literature say PCR entails in terms of concept and rehabilitation practice.

To address both these issues, an *a priori* scoping review was proposed, with the ultimate aim being to build a model for the conceptualization and practice of PCR, based on a thematic analysis of the existing literature. As the first step in developing the conceptual model, we conducted a scoping review to map the broad, all-time literature pertaining to PCR, focused on adults with physical impairments [6]. In this paper, we provide the scoping review results: the map of the PCR literature.

Hence, we review the amount, scope, and trends of the PCR literature inclusively by: paper type, publication date; country of origin; scientific journal; professional discipline; client population; setting; and, PCR topics. Finally, we synthesize the main subjects addressed and research methods per different categories of PCR papers (conceptual; design of new

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intervention; study of implementation, etc), using the study protocol's six inclusion categories as reference.

METHODS

The study protocol, previously published in an open-access journal, details the planned process for this scoping review [6]. Arksey and O'Malley's methodological steps [37], further updated by Levac and colleagues [35,36], guided the design and methods. For the feasibility of the review process by an international panel of authors, we searched for and included English language papers only, with no time, country, publication status, or study design restrictions.

As defined in the study protocol, we searched the literature using three major related scientific databases (PubMed, Scopus, CINAHL). The study protocol provides the full search strategy for one database: PubMed, in which the search strategy was first developed. Searches were run first in January 2016, and repeated in May 2018 for the time-period in between (January 2016 – May 2018). We carried out the planned snowballing searches (e.g. related citations tracking, searching of reference lists) over all references selected from the databases searches, and finally consulted experts to provide additional references; up to ten for each expert. Additional references could include grey literature, and were assessed against the eligibility criteria. We established a round of contact with 10 eligible experts, 8 scholars/researchers, and 2 knowledgeable insiders (i.e. persons experiencing disability or their close relatives who are simultaneously disability advocates). Five experts took up the role, including 1 knowledgeable insider, which met the protocol requirements. **Appendix 1** details the experts' names, position and known capacities to serve as an expert in this project.

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EndNote[a], a referencing software, was used to store and manage the publications data, and for helping removing duplicates.

In addition to being published in English, papers were eligible if they focused on the rehabilitation of adults with physical impairments and contained content relevant to PCR, i.e. fit into at least one of six inclusion categories for PCR-related topics, per the study protocol [6]. The inclusion categories were further clarified during the data selection process, to guide more objective and reliable eligibility decisions. **Appendix 2** details the inclusion categories along with further clarification notes, *a posteriori* added for more objectively supporting inclusion or excluding decisions (pages 1-3). The same appendix additionally provides a working definition of 'rehabilitation' (pages 4-5), which was missing from the study protocol. At all screening levels, pilot tests were run by two independent reviewers with a minimum of 5% of the references. With clarifications added, two independent reviewers conducted pilot tests, repeated as required: until reaching at least 80% agreement on eligibility decisions. Thereafter, two independent reviewers screened and then assessed the papers for eligibility, according to the following division of tasks: TJ and CSP fully completed the Level 1 screening (title and abstracts), and TJ, FB and CP completed three rounds of level 2 screenings (full texts) towards consensus, while a senior author (CC) decided on remaining disagreements. Reviewers had voice on selection decisions for papers they were authors. An appropriate record was kept on the agreed reasons to exclude papers at the Level 2 screening.

For this mapping exercise, data for publication date, journal, and country of origin of each paper's first author were directly exported from EndNote[a]. Inclusion categories were exported from the agreed inclusion decisions. Using data extraction tables, previously built by members of the research team, the paper aims, setting, professional disciplines addressed, numbers of participants, the primary issue tackled, and main methods applied were extracted

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by two independent reviewers (TJ; CSP). As typical in scoping reviews [35-39] and as defined in the protocol [6], methodological quality appraisal was not performed.

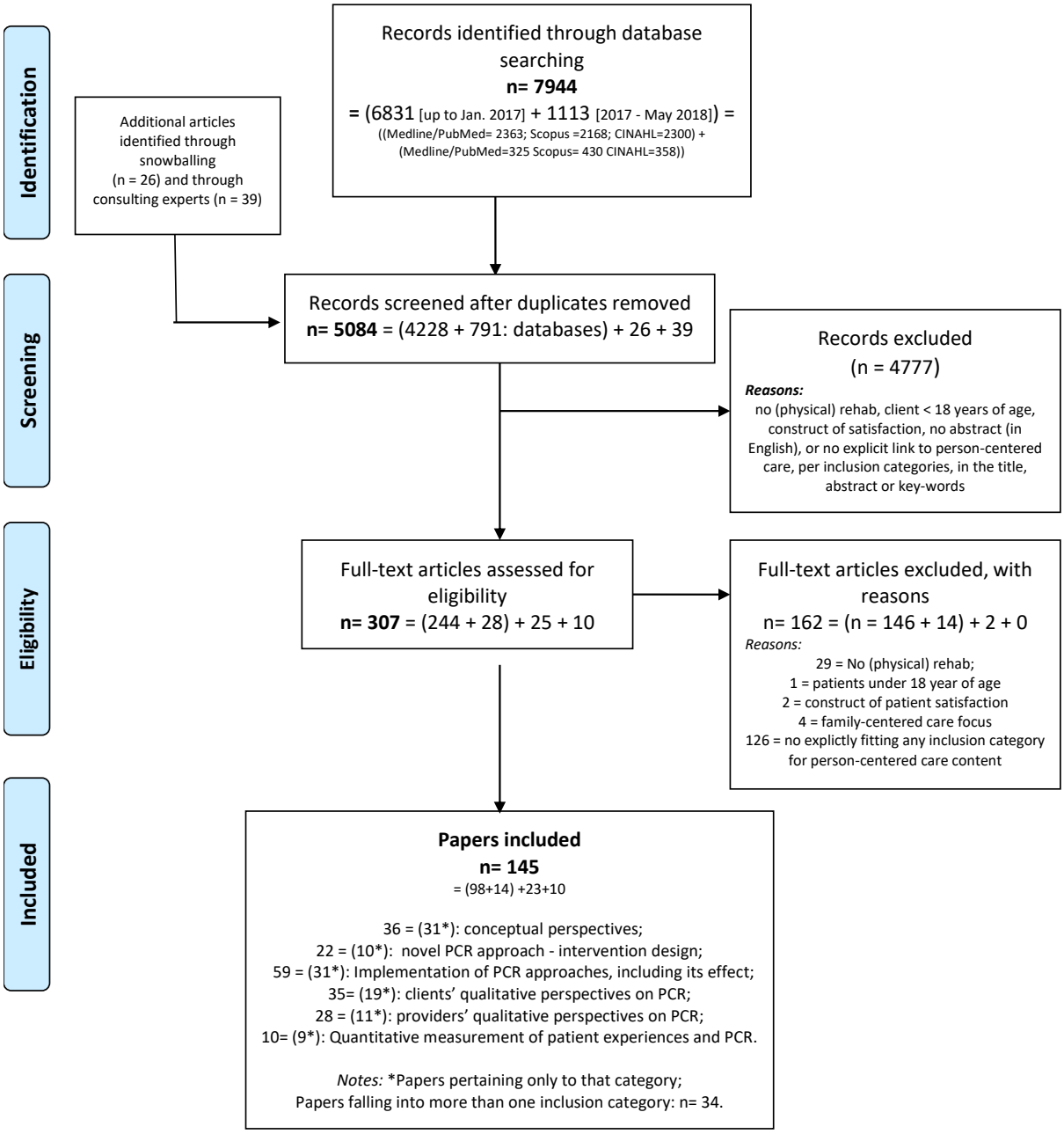
For the data analysis, descriptive statistics (e.g. sums, percentages) were computed for quantitative data, e.g. number of participants; publications per inclusion category. Charts were used to display and compare quantitative data (e.g. publications by country), using Excel.[b] Textual data, e.g. on primary subjects addressed and main methods applied, were subject to conventional content analysis [40]. Finally, the growth of publications per year was analyzed with linear or exponential regression analysis, retaining the model with the best fit according to visualization and r^2 values. Linear regression analyses using the analysis of variance (ANOVA), with log-transformed values for the exponential model, were applied to test the statistical significance of the growth of publications over the years.

Lastly, as reporting guidelines, we use the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Extension for Scoping Reviews (PRISMA-ScR) [40]. This extension became available after publication of the study protocol.

RESULTS

Figure 1 provides the PRISMA flowchart for this scoping review. Altogether, database searches yielded 7944 papers. The snowballing process over the selected references and the final consultation of experts added 26 and 39 references, respectively. With all duplicates removed, a total of 5084 unique records were screened for titles and abstracts. Of these, 307 full texts were assessed for eligibility, and 145 finally included.

Figure 1: PRISMA flowchart of the scoping review.



Appendix 3 lists the papers excluded after full-text review, along with the reasons why.

Appendix 4 details the full list of finally included papers, along with - in sequenced spreadsheets - the synthesis of their aims and methods and their key extracted characteristics.

A – Publication Trends - all papers included

Overall Trends

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Among included papers (n=145), 111 were of empirical scope, including 11 systematic or scoping reviews and 2 study protocols, while 34 papers were non-empirical, e.g. conceptual perspectives. Sixteen empirical papers came from 5 studies alone (e.g. RCTs); the remainder from unique studies. For all empirical papers included, data came from 13498 clients and 3849 providers. All but two papers were published in scientific journals, the exceptions being a doctoral thesis and a field guide from an international accreditation agency.

Publication growth over time

Figure 2 shows that the amount of included papers had exponential yearly growth from 2000 to 2017 (r^2= 0.65; p< 0.01). Interestingly, nearly a third of included papers (31%) were published in the last three years alone, while two-thirds of the conceptual papers were published in 2013 or before.

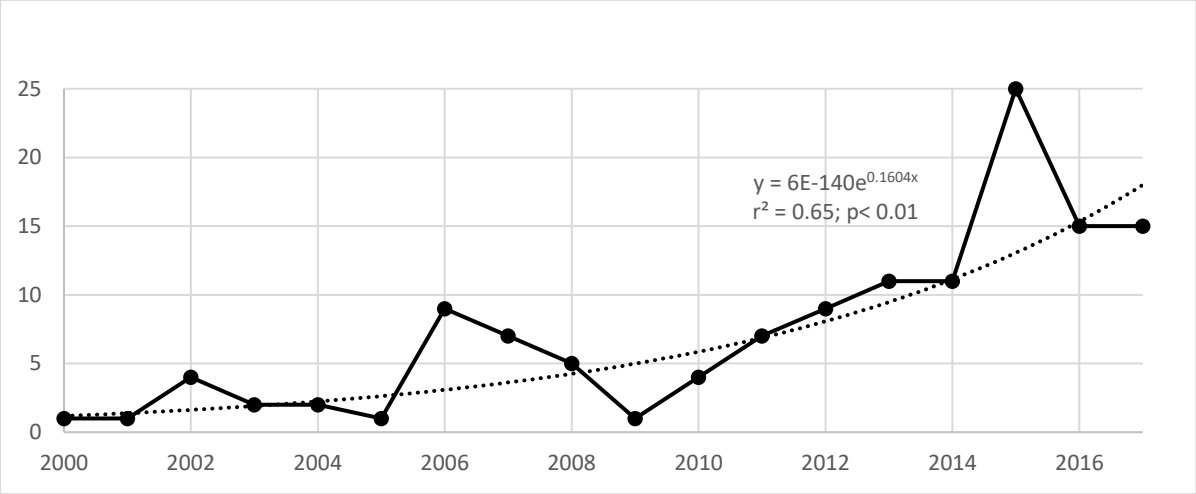

Figure 2: Publications per year from 2000 and 2017, and their growth: exponential regression model. Publications per year before the year 2000 were either residual or none.

Geographical Distribution

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Figure 3 shows New Zealand had the highest population-adjusted ratio of included papers, followed by Sweden, Canada, and Denmark. High differences existed across some countries, e.g. the United States' publication ratio was 45 times lower than New Zealand's.

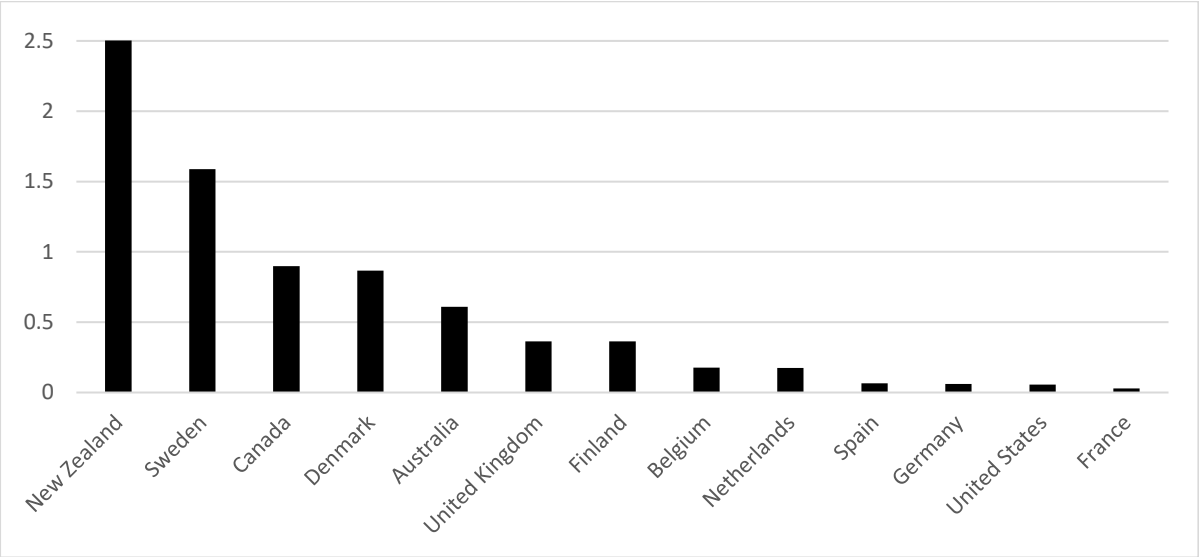

Figure 3: Publications per country (affiliation of the 1st author), adjusted per countries' population (1 million inhabitants: World Bank's population data, 2017); only countries with >1 publication.

Scientific journals

Figure 4 shows which journals published more than 2 included papers. The list is led by the *Disability and Rehabilitation*, which published 17.2% (n= 25) of the papers, followed by two Occupational Therapy (OT) journals, with 9.7% (n=14) and 9% (n=13). Only two of the twelve journals in the list were not specific to rehabilitation.

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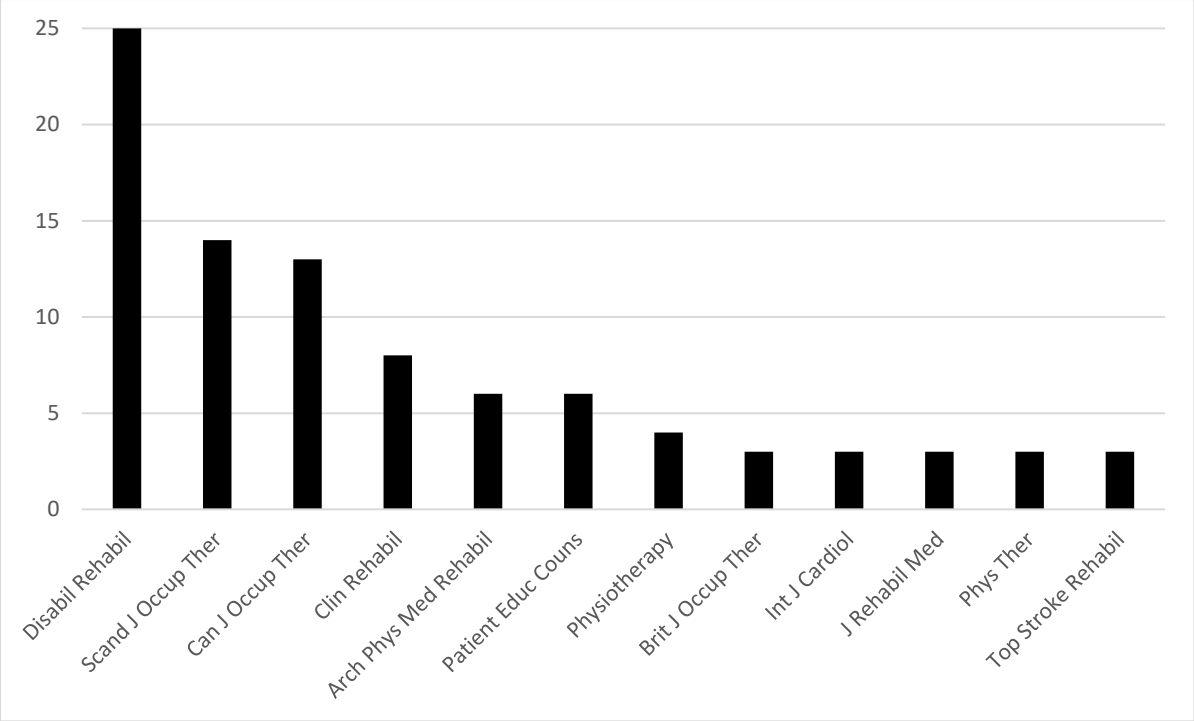

Figure 4: Publication per journals; only journals with > 2 included papers.

Professional Disciplines

Most papers (57.2%; n=83) did not focus on PCR within specific professions or if they did, they focused on more than one, including 8 papers addressing whole rehabilitation teams. Among those who had a single-profession focus, most (n= 37) focused on OT, 17 on Physical Therapy (PT), and 4 on Speech & Language Pathology. No other single profession was addressed by more than 2 papers.

Settings

About two-thirds of the papers (66.2%; n=96) were applicable to diverse types of setting, including 53 papers not specifying a setting, 15 addressing more than one, 10 addressing the care continuum or a care pathway, 6 focused on discharge planning or supported transitions (i.e. from one setting to another), 6 on organizations, 4 were set in the context of clinical education, and finally 2 papers addressed regional service systems.

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Among the remaining papers, which addressed single setting-types (n=49), 29 focused on inpatient rehabilitation, 12 on outpatient clinics, 4 on community-based services, 2 on acute care, and 1 on each of the following: primary healthcare, home, disability service, and municipality.

Client Population

Most papers (60.7%; n=88) were applicable to more than one health condition: 59 had no client population specified, 11 specified more than one, and 17 addressed large groups instead of specific health conditions: 8 neurological, 7 geriatric, 2 musculoskeletal, and 1 addressed overall chronic conditions.

Among those specifying health conditions, 40 addressed specific types of neurological conditions: 24 stroke, 7 acquired/traumatic brain injury, 5 spinal cord injuries, 2 aphasia, and 2 multiple sclerosis. Five papers addressed cardiac conditions, 4 hip fractures, and 2 rheumatoid arthritis. Each of the remaining papers addressed other, unique health conditions such as breast cancer.

PCR topics

Most papers (55.9%; n=81) focused directly on whole PCR practices or interventions, while the others addressed PCR from specific standpoints. Among the most prevalent, 21 papers addressed PCR in the context of goal planning, 8 focused on the care experience, 5 on discharge planning or care transition, 4 on teamwork, 4 on quality-of-care, 3 on engagement practices, and finally 3 on person-centered communication.

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B – Key subjects & methods - by inclusions category

Figure 1 details how many papers fall under each inclusion category, including those falling exclusively in each category, i.e. 34 papers fell into more than one. **Appendix 5** details which papers fall under each category or categories as well as their key issues and methods. We synthesize those subjects and methods by inclusion category, starting with the most represented.

Implementation of PCR approaches, including its effect (n=59)

In terms of subjects, 17 papers studied intervention effects of new PCR interventions: 7 on providers' PCR attitudes/behaviors, and 10 on rehabilitation outcomes. Additionally, 14 papers examined how a new approach to PCR was implemented into practice. Another 12 papers studied *how* providers apply PCR within regular practice, including what helps or hinders that process. Finally, 12 papers studied *the extent to which* PCR has been applied into practice – 6 of these also with a focus on the barriers/facilitators.

Methodologically, 8 papers reported results of Randomized Controlled Trials – including 3 follow-up results, 3 pilot/feasibility studies, 3 quasi-experiment designs, 2 pre- and post-test designs, and 2 observational studies comparing two or more groups. Still within the testing of interventions, 3 papers addressed process evaluations, and finally 3 presented sub-group or secondary analyses.

Still within the variety of methods employed, 12 studies were qualitative, especially for analyzing implementation factors: 4 were based on ethnography/practice observation, 3 on semi-structured interviews, 2 on focus groups, and 3 combined observations with interviews.

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Survey research, in turn, was used in 3 papers, examining the extent of PCR behaviors/attitudes in large participant pools. Five papers employed mixed-methods approaches, with survey and qualitative components. Six papers addressed case studies, yet typically for varying units (e.g. service, team, institution, clinicians, or patients). Other papers relied on routine data/medical records (n=3), action research (n=2), or practice improvement (n=1).

Finally, 3 systematic reviews fell within this inclusion category: on the extent of shared decision-making within a person-centered framing; on goal-setting barriers/facilitators and its patient-centeredness; and on how PCR has been addressed by the PT profession.

Conceptual perspectives (n=36)

Prevalent papers include 12 critical reflections on PCR values, concepts, or determinants, 7 conceptual reviews on PCR topics, 4 conceptual frameworks on PCR-related approaches, 3 conceptual or historical perspectives on PCR, and finally 3 authors' viewpoints about PCR. Three systematic reviews fell in this category, two exclusively: one focused on patient-centered goal-setting, and another on patient-centered self-management approaches.

Clients' qualitative perspectives on PCR (n=35)

Within this category, 8 papers addressed PCR related to goal-setting, 8 addressed qualitative experiences with PCR or PCR interventions, 3 identified key PCR themes or components, 2 addressed care participation with PCR as the backdrop , 2 addressed person-centered communication issues, 2 papers aimed to inform PCR measure development, and 2 papers addressed complex ethical issues for PCR: autonomy for discharge decisions, and the

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inclusion of relatives for PCR. Eight other papers addressed unique issues, such as couples' intimacy or access to a person-centered therapy service in rural areas.

Methodologically, 18 papers used semi-structured interviews, 3 used focus groups, 2 structured interviews, 2 multiple qualitative methods, 2 case studies, and 2 mixed focus groups with individual interviews. Finally, 6 systematic reviews were included, 4 exclusively in this category: 2 about stroke survivors' experiences of rehabilitation, 1 capturing spinal cord injury patients' experiences with interventions and PCR, and 1 mixed methods review of evidence exploring patient-centered goal setting in stroke rehabilitation.

Providers' qualitative perspectives on PCR (n=28)

Ten papers addressed goal-setting issues, 2 addressed PCR within a broader clinical reasoning or professional decision-making, 2 focused on ethical issues regarding the engagement of relatives and how that interferes with PCR, and 14 papers addressed rather unique topics, such as the issues of power and control in PCR approaches or therapeutic, patient-centered relationships perceived by rehabilitation professionals.

Methodologically, 13 papers used interviews – 1 structured, 6 focus groups, 2 multiple qualitative methods, 2 case studies, and 2 ethnography. Finally, 2 systematic reviews fell into this category, but none exclusively.

Novel PCR Approach - Intervention Design (n=22)

Novel, self-labelled PCR approaches were designed for the following issues: 4 whole rehabilitation or organizational approaches to PCR, 4 PCR approaches related to lifestyle, self-management, or transition to home, 4 person-centered assessment approaches, 3

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interdisciplinary team approaches to enhance PCR, 2 collaborative forms of goal-setting within a PCR framing, 2 metaphoric approaches to enhance clients' engagement, self-regulation and PCR, 1 profession-specific framework to guide PCR practice, 1 person-centered arts-based program to enhance clients' emotional well-being, and finally 1 drama play to increase providers capacity to deliver PCR.

Formal methodologies for intervention design were uncommon. Nonetheless, 3 papers reported (participatory) action research – including collaborative inquiry, 2 papers from the same study reported systematic literature search and interviews with staff, managers and patients, and finally 1 was directly driven by the results of a previous longitudinal study. Additionally, 2 intervention approaches were *a priori* published in study protocols. To a varying degree, all other papers (n=14) cite underlying theory, models, and research, or provide case examples, to support or illustrate the intervention design.

Quantitative measurement of patient experiences and PCR (n=10)

Among these papers, 6 refer to original scale development and validation (e.g. "Patient Reported Experience Measure", "Client-Centeredness of Goal Setting scale"), 1 refers to adaptation (short-form) and validation of an existing scale ("Client-Centered Rehabilitation Questionnaire") in new geographic context, and 1 paper used a cross-sectional survey design, measuring and comparing patient experiences of PCR. Finally, 2 systematic reviews fell into this category, 1 exclusively: to identify key dimensions of patients experience measures, with issues of PCR articulated.

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DISCUSSION

This scoping review synthesized the key characteristics and broader publications trends in the PCR literature, a vast and unchartered territory thus far. Among the 145 papers included, more than three-quarters (76.6%; n= 111) were empirical, while the remaining were conceptual perspectives. Therefore, beyond the needed conceptual developments and critical reflections, the rehabilitation field has been addressing PCR issues especially from an empirical point of view. Similarly, we found an exponential growth of publications over time, many systematic reviews addressing PCR-related topics, and finally a large amount of research participants (n=17347 clients or providers, in total). All these data point to a high and increasing focus of research publications on PCR issues.

Papers examining the *implementation of PCR approaches or its effect* were the most prevalent (n=59), which might have been driven by prevailing doubts on whether PCR is implemented as much as rhetoric suggests [15,33,41,42]. That amount of research can also be driven by the mixed results when PCR approaches are indeed implemented [43]: e.g., either improved [44,45] or worsened outcomes than usual care [44,46,47]. Interestingly, even within the same inclusion category, a wide range of methods existed, such as RCTs, other experimental research designs, process evaluations, qualitative methods, case studies, action research, or mixed-methods approaches. Qualitative research exploring perspectives of PCR, from either clients or providers, were respectively the second and third most prevalent category of included papers. All these data highlight the range of methods which have been used, and likely are needed, to understand the implementation of PCR practices, study its effects, or understand which experiences and care components pertain to PCR.

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Indeed, in the context of a subjective, contestable, and fluid concept such as person-centeredness, drawing on a diversity of methodological approaches may aid *crystallization* of the concept [48]. Hence, unlike *triangulation* which seeks congruence across methods and data sources, *crystallization* acknowledge the diverse, constructed nature of reality, drawing on multiple methods and data sources to develop a richer, nuanced, and therefore more in-depth understanding of complex constructs such as PCR; one that likely has no single experience, interpretation, operationalization, and likely cannot be fully addressed by a single research tradition.

Interestingly, the source of empirical data was predominantly from client populations with the number of client participants (n=13498) being 3.5 times higher than the number of provider participants. Clients' voices were therefore the most prevalent, which resonates with person-centeredness as a concept [49]. Nonetheless, providers' perspectives are important too, given that PCR is inherently a two-way process, i.e. is co-constructed between clients and providers, accounting for the personhood of both [7,50-52], while both clients' and providers' perspectives are germane, for example, to understand why PCR is or isn't implemented [53,54].

Over 20 novel, self-labeled PCR approaches were developed or described within the reviewed literature. These addressed a variety of subjects such as whole rehabilitation or organizational approaches, the interdisciplinary team, assessment methods, transitional or self-management approaches, and even patient intervention or staff training approaches, e.g. making use of arts, metaphorical approaches, or drama plays. This demonstrates multiple new ways and means through which PCR principles can be implemented in practice. Clearly, there is room for creativity in the design of novel PCR approaches. However, in only a few of these papers was there explicit mention of formal intervention development methods. Action research, intervention mapping, theory of change, and the systematic involvement of

stakeholders for intervention co-design would have been among the alternatives and, hence, have the potential to strengthen this emerging area of research [56-61].

Only a few papers drew on quantitative measures relevant to PCR, possibly because research on the measurement of patient experiences, including scale development, may have struggled to make an explicit link to PCR. On the other hand, limited conceptual work on specifying how PCR looks like in practice may contribute to the lack of a research on developing or using measures of PCR. While measures of "patient experience" are important and continue to be developed [62,63], they can be at best a proxy measure for PCR.

Adjusted for countries' population size, we found a clearly uneven distribution of included papers per countries. Countries in which public entities seem to have a stronger influence in healthcare - either through direct care provision, financing, regulation or stewardship – were substantially more represented; possibly reflecting stronger social values or longer history with PCR values and research. It may also reflect a stronger policy influence to drive – or dictate – a PCR practice and research agenda. Although, recent changing trends (e.g. the emergence Patient-Centered Outcomes Research Institute in the United States) may have not had yet enough time to change historical trends. Low and middle-income countries were not represented, which may reflect the existence of seemingly more pressing issues in many of these countries, such as the lack of rehabilitation resources [63-65].

Most papers included (57.2%) did not focus on single professional disciplines. Of those who did, OT and PT were respectively the most represented. While OT is rooted in a rich history of client-centered practice [31], the frequency of papers focused specifically in PT, including one recent SR [66], and the fact that most papers did not have a profession-specific focus, highlights the importance of PCR to more than one rehabilitation profession. By the same token, we found that the journals publishing more of the included papers had an inter-

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disciplinary, rather than a profession-specific focus. Additionally, most papers did not refer to single specific settings, including some addressing whole organizations, continuum or episodes of care, transition services, and even whole regional systems. Finally, most papers did not focus on sole health conditions. Altogether, these data reinforce the importance of developing PCR in the context of a systems approach, which transcends disciplinary boundaries and service-specific models of care [6,67].

Lastly, stroke and neurological conditions were among the most addressed health conditions, at odds with epidemiological data pointing to higher global burden of disability from pain and musculoskeletal conditions [68], and the relatively balanced publication data between those conditions in the broader rehabilitation field [69,70]. This finding may reflect that there may be added complexity embedding PCR for those with neurological sequelae, which can disrupt many aspects of life, including sense of self and communication [71-73]. While there may be extra challenges implementing PCR in these situations, it does not necessarily mean that PCR is more valuable, worth developing, or even entirely different at its core when applied to the rehabilitation of neurological conditions – especially considering that PCR focuses on the individual *person*, not a type of *patient* who has a certain disease or disability.

Limitations:

This review has several limitations. First, articles not published in English were excluded. Second, although we aimed to include literature other than peer-reviewed, notably through the snowballing and experts' recommendations, only 2 such papers were identified and included. Third, country of origin was based on the affiliation of the 1st author – disregarding the possibility that co-authors may be from other geographical regions. Fourth, we included no experts from low or middle-income countries, even though one had global health

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expertise. This limitation, along with the inclusion of English-language papers only, may have contributed to the lack of identification of papers from those countries. Fifth, we only searched three major scientific databases (Medline/PubMed, Scopus, and CINAHL). Other large databases (e.g., Embase, Web of Science) were not searched. Embase adds to Medline/PubMed mostly in biomedical science – although typically with modest impact on retrieving additional relevant articles [74]. The Web of Science has higher cross-disciplinary coverage, which would be complex to manage in this topic [6]. Profession-specific databases (e.g. OTseeker, PEDro) were also not searched, as we aimed to consider content published only in profession-specific journals that were, cumulatively, indexed in at least one major health database. Sixth, given the large amount of initial entries, we needed to enlarge our review team beyond those contributing to the study protocol, and redistribute tasks accordingly. As such, this marked a minor deviation from the initial plan published in the study protocol. Seventh, full papers that are relevant to PCR but did not report related terms in the title, abstract or keywords may have been undetected. Eight, relevant papers published within the last 2 years may have been undetected due to typical delays in the indexation process (e.g. for Medical Subject Headings in Medline/PubMed), which we partially used in the search strategy; this may affect inclusions for the more recent years as well as the publication growth analysis. Ninth, the inclusion criteria published in the study protocol was insufficiently detailed. As such, clarification was added after the initial pilot screenings to increase inter-rater agreement and reduce subjectivity in applying the criteria. Tenth, we did not synthesize results or conclusions of the included papers, given the large amount of inclusions, the papers' inherent heterogeneity – even within the same inclusion category, and lack of methodological quality assessment. However, it is possible that such endeavors can be carried out later for subsets of the data. Finally, in this paper, we do not analyze how the reviewed literature approaches the concept and practice of PCR or what it entails; this is

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subject to a different type of data extraction and a thematic analysis which is undergoing, and will be reported in due course – as a model for the conceptualization and practice of PCR, emerging from this body of literature.

CONCLUSION

This scoping review is the first to map the type, amount and key features of the English-language literature on adult PCR, mostly that published in scientific journals. It charts how and how much the rehabilitation literature has been approaching PCR topics, notably in terms of publication growth, client population, journal of publication, country of origin, care setting, PCR topics, and finally issues and methods per type of included papers. Stakeholders can use the identified trends, map of the literature, and the collated citations to inform further PCR research and practice.

Among trends identified, we observed an exponential growth of publications on PCR topics, and most came from an empirical point of view. The observed heterogeneity in the methodologies used, even for papers falling into the same inclusion category, underscores the very practical need to approach PCR topics and their complexity from the lens of diverse research methods and paradigms. Furthermore, opportunities emerged for further developments, such as the use of formal and/or participatory methods to develop PCR approaches, and opportunities for a more balanced development of PCR publications by country.

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Finally, the high prevalence of papers focused on multiple professions, settings, or health conditions reinforce the need for developing a transdisciplinary, trans-service model of PCR, to be derived from a thematic analysis of this body of literature.

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Suppliers

a EndNote X8, Clarivate Analytics.

B Microsoft Excel 365, Microsoft Corporation

Figure Legends

Figure 1: PRISMA flowchart of the scoping review

Figure 2: Publications per year from 2000 and 2017, and their growth: exponential regression model. Publications per year before the year 2000 were either residual or none..

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Figure 3: Publications per country (affiliation of the 1st author), adjusted per countries' population (1 million inhabitants: World Bank's population data, 2017); only countries with >1 publication.

Figure 4: Publication per journals; only journals with > 2 included papers.