

Section Six

CONCLUSIONS

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The conclusions of this doctoral thesis embrace the thesis major products, the thesis major limitations, and a sub-section outlining implications for the field of Health Psychology coming with this thesis development.

1- Thesis Major Products

Despite the major limitations that can be pointed to this thesis process and final products (later analyzed), the outcomes, or end-point, of this doctoral thesis brings an input in the quality reforms prescribed to the actual socio-political context of healthcare and healthcare systems. We mean the development and implementation of transformational changes for quality, though a system of aligned quality-initiatives, with healthcare systems as broader unit of analysis.

This scenario is particularly prevalent in the United States (US) of America, with internal reforms undergoing and being prepared. It includes the context of US PAC Rehabilitation systems, services and care also being a political target for systems-based reforms for quality ⁽¹⁾. Thereby, such context remained as the socio-political context of development, support and envisioned applications of this thesis.

The establishment of our set of objectives, as there defined, was initially guided by a long-term vision for the subject matter - to develop what we called as a US 'PAC Rehabilitation Quality System'. This is an aligned system of effective and meaningful PAC Rehabilitation quality-initiatives. Then, in a backward fashion (a developmental perspective also reflected in many aspects along thesis process), we established our thesis goal and specific goals accordingly. It represents a vision and long-term outcomes-oriented approach towards developing and deploying present initiatives, as guided by a long-term vision.

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Furthermore, we were seminally guided by a systems thinking and systems-redesign perspective, which was one of the major underlying rationales behind this thesis development (outlined in Background). This was also the rationale behind the transformational change recommendations for quality in healthcare systems made by the landmark ‘quality chasm’ report about a decade ago ⁽²⁾. Therefore, this thesis employs a systems thinking approach to the scope of PAC Rehabilitation quality and quality-initiatives, with the resultant preliminary recommendations also fitting within the larger scope of US healthcare systems re-designing features and socio-political reforms.

1.1 Preliminary Recommendations

The final thesis product is a set of preliminary recommendations towards activating the development of what we called as a ‘PAC Rehabilitation Quality System’. The scope of presented preliminary recommendations primarily focuses on possible external-level structural action and supportive research to be taken under a strategic roadmap towards the envisioned ‘PAC Rehabilitation Quality System’.

With such regards, we came to a two-level hierarchy of preliminary recommendations: overarching recommendations and possible operational recommendations we point out recurring to the process, results and specific discussion made over our supportive reviews. The two-level hierarchy determines the set of outlined operational recommendations might be defined, shaped, redefined, transformed, made specific, or complemented by the action and the mutually-influenced process of the two entities outlined as our overarching recommendations.

The overarching recommendations are directed to the development of the following entities with a reciprocal and mutually-adjusted process:

1. PAC Rehabilitation Consensus-Building Partnership for Quality.
2. Interdisciplinary Center for Developing PAC Rehabilitation Quality-Solutions.

These entities might work in a close collaboration and complementary processes for developing strategic, infrastructural and influential input, as well as developmental and planned research action towards supporting the development and maintenance of an effective and meaningful system of PAC Rehabilitation quality-initiatives.

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By its turn, the operational recommendations represent a possible starting-up action plan towards the envisioned 'PAC Rehabilitation Quality System'. They are built upon the actual initiatives being planned and applied on the field, yet completing their scope, mostly by targeting sub-optimally addressed quality dimensions, or those features with greater potential to structurally support a transformational change for quality and quality-initiatives in the PAC Rehabilitation systems, services and care. However, we denote these and other possibly applied recommendations might pass through a development, refinement, testing, and deployment process coordinated by the joint process of the two highlighted overarching recommendations.

The four preliminary operational recommendations we make in the thesis are to develop:

1. An external-monitoring of consumers experiences: ensuring patient/family-centeredness through an external monitoring-system;
2. The interpersonal dimension of care: becoming a measurable and improvable quality-dimension;
3. A uniform clinical-registries data-system: for practice, quality-assessment and research purposes;
4. An improvement data-system: supporting PAC Rehabilitation quality-improvement initiatives and quality-improvement research.

The first two recommendations, which might be developed in parallel, try to ensure the consumer-centeredness of PAC Rehabilitation quality-initiatives and care. The first envisions a the development of a consumer-centered outcomes measure to become part of an external outcomes/quality-monitoring system which is being prepared on the field but not containing such a measure, while the second recommendation targets the specific and operational development interpersonal dimension of PAC Rehabilitation care, which represents a major determinant and dimension of patient/family-centered outcomes. Besides, the development, measurement and improvement of such specific interpersonal dimension of care (historically sub-educated and sub-developed) - particularly in combination with specific team-work improvement approaches (more recently developed) - it might seminally support a transformational change for quality of PAC Rehabilitation care, also potentially interfering with PAC Rehabilitation health-related outcomes – the subject specifically developed by one of supportive reviews (1st review – part B).

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The third operational recommendation presents as the more complex to be developed and deployed on the field, yet it represents a common infrastructural platform and information system with enormous potential benefits and synergies for PAC Rehabilitation practice, quality-initiatives and research. It presents a recommendations complex to develop because it requires a set of pre-requisites not yet totally accomplished, and mostly because it would require an enlarged uniformization in the way professionals register information, care goals and plans, and care activities. Furthermore, it requires an enlarged use of Health Information Technologies. It aims to facilitate on-time evidence-based decision-making, on-time and accurate access to shared information for coordination of care. In addition, it might facilitate the registering, upload, storage, and feed-back analyzes of clinical data used for further planning of: services, care, quality-improvement; as also for the use in practice-based research studies.

Considering some leading organizational contexts, it is a recommendation close from what are already being done. However, achieving an enlarged adoption, at a national basis, the generalized adoption of such kind of systems is largely known to be very complex to plan, manage and successfully achieve on larger scales⁽³⁾.

Finally, this uniform clinical-registries data-system might be cross-linked with quality-information collected by the external outcomes-based quality-monitoring system, with both serving as a comprehensive data-basis for quality-monitoring, public-reporting and quality-aligned payment system.

The fourth and last operational recommendation (the one we expect can be only fully deployed later on time) embraces what we called as an 'Improvement Data System'. It means a system, mostly electronic-based, that on-timely guides the development and deployment of PAC Rehabilitation quality-initiatives, as well as it simultaneously collects information about PAC Rehabilitation quality-improvement journeys or initiatives for later being time-series analyzed. Such analyzes might be made by crossing information with the comprehensive data-basis for quality-monitoring, public-reporting and quality-aligned payment system.

A quantitative-based and qualitative analyzed periodic report might be sent back from the central system to providers about adequacy and effectiveness of the quality-journeys, outlining an action-oriented focus and guidance for optimal improvement actions and approaches to take, as tailored to cross-linked information on organizational quality profiles and quality journeys.

1.2 Supportive Reviews also as an independent thesis outcome

The set of preliminary recommendations was informed by a planned set of supportive reviews, as delimited in Objectives, and presented as thesis Results. But besides the supportive role for the design of these preliminary recommendations, reviews can have other applications beyond this thesis, thereby being also an independent thesis outcome.

Although such a statement can be generally framed for all our supportive reviews, as analyzed in the each review Discussion, this is particularly applied to the 1st review, which develops a specific PAC Rehabilitation quality conceptual framework; as well as applied to the 1st review - part B, which specifically develops the literature sub-addressed interpersonal dimension and hypothesized linkages with PAC Rehabilitation health-related outcomes. The specific applications of these two reviews, beyond this thesis development, were initially framed and led us to the development, synthesis and presentation of these reviews in a format suitable to be later turned into an international peer-review publication – meaning with an enhanced emphasis in present these results as much synthetically as feasible.

Indeed, the specific PAC Rehabilitation quality framework (1st review) - mostly after recommended refinement, consensus validation and specification as granularly presented at Discussion - can be turned into a ground basis for a shared stakeholders understanding of PAC Rehabilitation quality, serving as conceptual background for the design of comprehensive PAC Rehabilitation quality-initiatives.

The 1st review – part B, specifically addressing the hypothesized conceptual pathways linking the PAC Rehabilitation health-related outcomes with its specific interpersonal dimension, can trigger interest not only for empirically showing the hypothesized linking mechanisms and mediating variables (broadly framed as psychosocial engagement outcomes), but also by raising interest towards the improvement of PAC Rehabilitation health-related outcomes, as made through the systematic definition, development, measurement and improvement of the specific PAC Rehabilitation interpersonal dimension of care – something we made reflect on our 2nd operational recommendation.

2 – Thesis Major Limitations

This thesis has several limitations undermining its validity, effectiveness and utility. There are for instance methodological limitations pointed to each supportive review, achieving granular representation in the Discussion of each review, made independently. Herein, we focus on the more global perspective of the limitations that can be pointed to the thesis as a whole, with four major groups of limitations outlined.

First of all, this thesis is framed within a very ambitious, large-scale, long-term envisioned objective. The accomplishment of such long-term objective depends on much more a single research-line, single study or activity of a single researcher. Beyond, it cannot be even accomplished by an entire research community. Rather, it requires a great alignment among many related stakeholders for such US ‘PAC Rehabilitation Quality System’ could become deployed in the field as a powerful mean to support a transformational change for quality in the addressed healthcare area. However, an alignment of visions, perspectives, roles, initiatives and actions among an enlarged range of PAC Rehabilitation stakeholders is clearly not an easy task to be achieved. Power struggles and efforts to maintain the *status-quo* represent the social-behavioral response norm towards such kind of great prescribed changes. Indeed, it is increasingly acknowledged the complexities of such broader social-political context - more than the lack technical capacity and resources - can undermine the deployment any set of recommendations with a transformational focus such those here proposed⁽⁴⁾.

Trying to overcome such major limitation, we directed our first overarching recommendation to the formal establishment of a PAC Rehabilitation consensus-building partnership for quality, mostly with the underlying intent to upfront address such kind of undermining socio-behavioral features and expected difficulties. Yet, the own establishment, enlarged engagement for representativeness, and the development of the process and activity of such formal partnership that is it-self consensual might represent the very first major challenging task to overcome.

A second major limitation of this thesis relates with the process of setting our preliminary recommendations towards activating the development of a ‘PAC Rehabilitation Quality System’. It represents a set of integrative preliminary recommendations that were grounded in the process and results of our supportive reviews, yet these reviews are not free of

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methodological considerations and limitations (further analyzed). However, beyond, there was any very strait and easy reproducible pathway between the data presented in our supportive reviews and the drawing of our set of preliminary recommendations. In other words, different researches based in the same supportive process and supportive results might come to a very different set of integrative preliminary recommendations. Such variation accounts by the elevated degree of influence regarding authors' interpretation and creativity necessarily putted on this kind of solution-based integrative preliminary recommendations.

Accounting for such limitation, which remains an intrinsic thesis property, we *a priori* defined that the scope of our preliminary recommendations would be presented in Discussion section, despite representing the main thesis goal. In fact the thesis Results are constituted by the product of our supportive reviews, being the more objective research data coming from this thesis development.

However, the third major limitation of this thesis is that even the supportive reviews placed at Results are not totally objective in process and results, as compared to the gold-standard of Cochrane-style systematic reviews. This is a feature inherent to the wide scope^(5; 6), integrative⁽⁷⁾, and the realist (complex-based)⁽⁸⁾ review approaches we used to build our tailored review approaches, as widely supported on Methods. Such kinds of review approaches do not totally avoid, and can even encourage⁽⁸⁾, the value a certain degree of interference of the authors' subjectivity for the success and feasibility of review process and final product – particularly if it is a complex-based product such those addressing health policy and health systems interventions. This is in clear contrast to the underlying assumptions of the Cochrane-style systematic review approach, thus *a priori* assuming as limitations the non-total reproducibility and non-total representativeness of the reviews process and results. These limitations are pointed to reviews and their own value, as well as it secondarily brings limitations to the preliminary recommendations based upon these supportive reviews.

A fourth major limitation of this thesis process and the thesis final outcomes relates with the fact it was conducted mostly by a single author (a doctoral thesis intrinsic requirement), even receiving formal orientation and informal consultation and collaboration received from experts of some particular sub-areas addressed, as it happened. Despite such critical external help, and also despite the author had incurred into a systems thinking and inter/trans-disciplinary learning journey to become progressively able to accomplish the

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applied inter/trans-disciplinary scope of these thesis goals and requisites, it is unfeasible to think such broad and ambitious envisioned accomplishments could be developed in their maximum potential mostly coming from a single author, independently of major areas of expertise.

Acknowledging such limitation, besides the consultation seeking efforts, we took wording caution from the very beginning and continuously along all paper to define the set of recommendations as being preliminary recommendations; acknowledging this set of preliminary recommendations might be framed as author-made supported possibilities, and better seen as a paper able to activate more concrete attention and discussion towards this subject matter.

Finally, the awareness that such very complex, but also very important, matters shall be addressed by a much broader inter/trans-disciplinary approach, led us to place focus on our 2nd overarching recommendation – meaning to develop an interdisciplinary center developing PAC rehabilitation quality-solutions. Such a center might be developed to work not only on an occasional basis, but continuously under a structural and organized process and formally established entity, working inter-dependently with the PAC Rehabilitation Quality Partnership for Quality (1st overarching recommendation). Thereby, we can state that from the thesis major limitations we built our major recommendations.

3- Implications for the field of Health Psychology

Rather than a study coming from a single discipline or body of knowledge, this thesis is better framed as an inter/trans-disciplinary-informed approach designed to address a complex and multi-determined health policy problem. Indeed, the results of the thesis and its final product, or end-point, integrates inputs from different areas of knowledge as applied to a wide systems-based and problem-solving approach, in this case focused on quality and quality-initiatives in the US PAC Rehabilitation system, services and care.

Therefore, if we want to label this thesis in a research field, it might be primarily called as a health services research and mostly health policy research study. These are applied research fields by nature, informing complex health policy decisions by integration of knowledge coming from many bodies of knowledge. Such disciplines are broadly medicine and other

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health disciplines, economy, management, engineering, and many applications of these areas.

However, we might neither forget, nor diminish, the critical value of the broadly called social sciences in a journey for solving so complex socio-technical problems such is the need for a transformational change for quality of healthcare systems, in case applied to PAC Rehabilitation systems, services and care. Particularly, applied social sciences that are already addressing health issues - such as sociology of health or medicine and the health psychology - remain as a critical background to be embedded in complex-based, socio-technical, and systems-based solutions needed for the also complex-based, socio-technical, and systems-based quality problems.

Indeed, it is increasingly recognized that this type of health problems need inter- and trans-disciplinary research and developmental approaches, for instance reflected into our yet outlined 2nd overarching recommendation relating with an interdisciplinary center developing systems-based PAC Rehabilitation quality-solutions. The body of knowledge of health-related social sciences, including health psychology, might become reflected in the integrated solutions resulting from the interdisciplinary process of the recommended center.

Moreover, the particular research agendas of these sciences might be designed accordingly to the interdisciplinary and systems-based formulations of complex health problems, following their backwards diagnoses of causes and 'causes of causes' of these problems. This is a health psychology implication for instance well-aligned with a vision of the US entity responsible to fund this body of knowledge⁽⁹⁾.

The body of knowledge of health applied social science, such as health psychology, informed such thesis developments in many of these different parts, and in many different ways. Bellow, these are analyzed, followed by its implications.

First, health psychology underlying informed the components of the active consumers' role for quality of their health and healthcare, including the features of active engagement with quality-informed choice and systems re-design, as well as the shared decision-making and mostly the self-management of their health, health determinants and disease conditions. This is a field health psychology research is yet heavily addressing, with an extremely justified purpose, thus remaining as a great area for further developments.

Second, health applied social science, including health psychology, represents a body of knowledge integrated in the features of the in-developing improvement and implementation

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sciences, either if it embraces re-designing systems of care and practitioners behaviors, either if it comes to translate and implement tested innovations into routine practice. Both require difficult-to-achieve changes in mind-sets, habits and behaviors of individual practitioners, managers and healthcare leaders, as well as of systems, organizations and professional groups. Such changes in individual and collective mind-sets and behaviors should be informed by the existent knowledge and new developments of these health-applied social sciences. Indeed, as we already mentioned in these conclusions, the difficulties related with behavior, social, and broader political change remains as the great undermining source for the achievement of the so-called transformational change for quality in healthcare systems, much more than the technological aspects, which are achieving maturity⁽⁴⁾. The complex matter of healthcare reforms and improvement (which necessarily involves individual and collective change in mind-sets and behaviors) is an urgent field of application and development of health-related social sciences research, including health psychology, being not so prevalent today as it should be in the future.

A third contribution of the health psychology knowledge and theories to this thesis was more directly reflected in the review (1st review - part B) addressing the subject of how PAC Rehabilitation health-related outcomes could be influenced by the PAC Rehabilitation specific interpersonal dimension, which was shaped accordingly. Then, it become reflected in specific preliminary recommendations related with the systematically development of the interpersonal dimension of care into a measurable and improvable dimension, with ability to influence quality and outcomes of PAC Rehabilitation services and care.

Such recommended developments might be informed by actual knowledge and advances of health psychology, in outcomes-based, or end-points based, developmental perspective as it was employed in the 1st review – part B. Indeed, the psychosocial engagement variables represent central mediating variables in the pathways linking the interpersonal process and PAC Rehabilitation health-related outcomes. These variables represent the natural field of health psychology. Thus, the definitions and developments in the specific PAC Rehabilitation interpersonal process might be framed according such health psychology knowledge and further developments.

Such contribute of behavioral sciences was called for the definitions and development of the interpersonal dimension of care more than two decades ago by the most recognizable seminal paper framing the quality of healthcare⁽¹⁰⁾. Over these years, such call still remains

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applicable to the specific scope of PAC Rehabilitation. Thus, it becomes a particular application field to be explored and addressed by health psychology applied research.



References (Conclusions)

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