

Doctoral thesis

Continuity of health care across care levels in different healthcare areas in the Catalan national health system: The patient's perspective

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UNIVERSITAT AUTÒNOMA DE BARCELONA

Barcelona, December 2015

*Learn from yesterday, live for today, hope for tomorrow.
The important thing is not to stop questioning.*

Albert Einstein

Acknowledgement

Hace siete años decidí venir a Barcelona para realizar un Máster en Salud Pública, en una ciudad muy atractiva que se había puesto de moda por el *lifestyle* en el que solo podemos soñar en los países del norte. Tenía curiosidad por conocer la cultura española y ganas de enfrentarme al reto de estudiar en un idioma diferente y en un país que no había visitado antes. Fue un reto personal. Los dos años que pensaba estar se convirtieron en siete años y he disfrutado mucho de cada uno de ellos. Durante estos años he crecido personalmente, he adquirido nuevas habilidades, he conocido el mundo de la investigación, y he llevado a cabo una tesis. Además, he conocido a gente maravillosa que me han inspirado y me acompañado durante esta etapa de mi vida, de lo que estoy muy agradecida.

Primero quiero agradecer a mis directoras de tesis; María Luisa por haberme ofrecido la oportunidad de realizar la tesina y la tesis bajo su dirección, la confianza que ha depositado en mí desde la primera entrevista, y por haber tenido la paciencia de enseñarme investigación cualitativa y responder a mis miles de preguntas; e Ingrid por sus constructivas sugerencias de mejora de mis artículos, los debates útiles sobre los conceptos y sobre todo por animarme con su sonrisa a seguir adelante. Quisiera agradecer también a mis tutores de tesis, Josep María Jansà, que me acompañó durante los primeros años y Montserrat Ferrer que ha estado dispuesta a apoyarme en los últimos meses antes de la entrega. I would also like to say thanks to Sarah Thomson and Juan Tello for having given me the opportunity to visit their institutions in London and in Copenhagen; two research visits I very much enjoyed.

También quería agradecer a mis queridas compañeras de trabajo, Marta por su disposición de ayudarme en cada momento, Nuria por su apoyo administrativo imprescindible, Irene con quién tuve la oportunidad de compartir algunos talleres en América Latina y quién, junto con Jordi, me enseñaron algunos lugares preciosos en Cataluña, y Viqui por su bailes que me alegraron el día. Finalment, també voldria agrair al meu company Josep Lluís pel temps compartit a migdia en el parc i la seva paciència en ensenyar-me el català.

Agradecer también a los protagonistas, los pacientes y usuarios de los servicios de salud que aceptaran participar en los estudios, porque sin ellos esta tesis no habría sido posible.

Von ganzem Herzen möchte ich meinen Eltern danken, den allerbesten, dafür, dass sie mir in jeder Situation beistanden, mich während meiner Ausbildung moralisch und finanziell unterstützten und bei den unzähligen Umzügen von einer Stadt zur anderen tatkräftig mit anpackten. Sie sind wahre Schätze! Herzlich danke ich auch meinen beiden lieben Schwestern, Helen und Anja, die ich gerne viel näher bei mir hätte, denen ich mich aber dennoch immer sehr nahe fühle und dem kleinen Oskar für die Freude die er uns in den letzten eineinhalb Jahren bereitet hat. Ich danke Kai, meinem Schwager, für die gemeinsamen tollen Wanderungen und Reisen, seine

Hilfsbereitschaft und Freundschaft, und auch Hasantha, meinem zweiten Schwager, für seine bewundernswerte Herzlichkeit und Güte.

Ein Dankeschön auch an meine Verwandten, besonders an meine Cousine Teresa, mit der ich seit klein auf gemeinsam die Welt entdecken darf, für die vielen lustigen Stunden und unvergesslichen Abenteuer, und an meine Freundinnen in Vorarlberg, besonders aber an Jacqui, mit der ich seit beinahe 30 Jahren eine unzertrennliche Freundschaft genieße.

Quería dar mil gracias a mis mejores amigos en Barcelona que se convirtieron en mi familia en Cataluña y me dieron la energía positiva para escribir la tesis: Yulia, amiga desde mi llegada a Barcelona, por las horas paseando, charlando y bailando, vivimos Barcelona juntas; Steffi, que también conocí al inicio del Master, por compartir tantos momentos bonitos conmigo; Anna, por mimarme con pasteles riquísimos y los instantes compartidos meditando en la montaña y practicando yoga en la playa durante la salida del sol; Rosa, por siempre estar disponible cuando hacía falta y haber contribuido a que tenga una vida más sana y alegre; Anica, Ramón y Héctor por hacerme adicta a los partidos de vóley playa que me permitió desconectar de todo, Alfredo por las horas y horas bailando con música latina; to Paul, for the numerous interesting hours-long conversations reflecting about the world; and finally I would like to thank my boyfriend Dimo for the beautiful hours spent together in Barcelona and other parts of Europe and in particular for motivating me to wrap up the thesis when it was in its last stage.

This thesis has only been made possible because of the support and love received by my family, friends and colleagues.

Danke. Gracias. Thank you. Gràcies. Благодаря.

Preamble

The present thesis was developed within the research area of care integration of the Health Policy and Health Services Research Group (Grup de Recerca en Polítiques de Salut i Serveis Sanitaris) led by the Health Policy Research Unit (Servei d'Estudis i Prospectives en Polítiques de Salut), which forms part of the Consortium for Health Care and Social Services of Catalonia (Consorci de Salut i Social de Catalunya); a public entity that groups public and private non-profit health providers of the Catalanian national health system. The research unit has long standing research experience in care integration, especially in Catalonia but also in different countries in Latin America.

The thesis presents results of two projects developed in Catalonia: *Integrated health care networks in Catalonia* (Organizaciones sanitarias integradas en Cataluña; PI04/2688) and *The relationship between continuity of care and coordination among care levels in different healthcare environments* (La relación entre continuidad y coordinación entre niveles asistenciales en diferentes entornos sanitarios; PI10/00348); both financed by the Institute of Health Carlos III and European Regional Development Fund (FEDER).

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ABSTRACT

Introduction

Specialization in health care, rapid advances in technology and the diversification of providers cause that patients receive care from several professionals of different disciplines in various settings and institutions. These trends together with demographic and epidemiological changes increasingly expose the patient to fragmented care delivery. Fragmented care, or care that is insufficiently coordinated between providers, can be harmful to patients due to duplication of diagnostic tests, inappropriate poly-pharmacy and conflicting care plans. Health systems and organizations may introduce an array of interventions to facilitate the coordinated delivery of services to individuals and populations, as for example the implementation of integrated health care networks. They can be defined as networks that provide or arrange to provide a coordinated continuum of services to a defined population and are willing to be held clinically and fiscally accountable for the outcomes and health status of the population. Their ultimate objectives are to improve global efficiency, equity of access and quality of care, by means of improving care coordination and continuity of care across the care levels. Continuity of care is the patient's perception of the coordination of services and can be defined as how one patient experiences care over time as coherent and linked. It embraces three types: continuity of clinical management and information across the care levels and continuity of relation with the primary and the secondary care physician. In Catalonia (Spain), integrated health care networks emerged as a response to the diversity of providers in the management of primary, secondary and long-term care. Their performance, however, has mainly been studied from the providers' perspective, i.e. regarding care coordination. Studies on the perceptions of continuity of care, its influencing factors and consequences from the point of view of healthcare users of the national health system of Catalonia are still scant.

Objective

To explore the user's perception of continuity of health care across care levels in different healthcare areas in the Catalan national health system, as well as its influencing factors and consequences on quality of care, in order to contribute to its improvement in the healthcare system.

Methods

The research consisted of three individual studies addressing different aspects of continuity of care.

- 1) Analysis of the international evidence on continuity of care from the patient's perspective, employing a meta-synthesis of qualitative studies based on a literature search in various electronic databases (Medline, Web of Science and Cochrane Library Plus). The search strategy included the combination of 'continuity of care' or linked key

terms, qualitative studies and the patient's perspective. 25 original studies published from 1999 to 2009 that complied with the inclusion criteria were retrieved and included in the synthesis. Content analysis was conducted by the identification of themes and categories and the aggregation of findings of the three types of continuity of care.

2) Analysis of COPD patients' perceptions of continuity of care in four integrated health care networks of the national health system of Catalonia, using a multiple-case study of COPD patients. A theoretical sample was selected in two stages: (i) four Catalan integrated healthcare networks and (ii) two study cases of each network consisting of one COPD patient, his/her primary care physician, pulmonologist and medical records. Data were collected by means of individual semi-structured interviews with patients and physicians and the review of clinical records. All interviews were recorded and transcribed verbatim. A thematic content analysis segmented by network and cases with a triangulation of sources and the participation of different analysts was carried out.

3) Analysis of continuity of care in different healthcare areas of the Catalan national health system focusing on the three types of continuity of care, the factors influencing it and its consequences on quality of care. A theoretical two-stage sample was selected: (i) study contexts: three healthcare areas representing the diversity of management models for the delivery of services, and (ii) healthcare users. Individual semi-structured interviews with healthcare users (14 to 18 per area) were employed. Data collection stopped when saturation was reached. All interviews were recorded and transcribed verbatim. A thematic content analysis was carried out, segmented by study area, with a mixed generation of categories and the participation of different analysts for guaranteeing quality of results. Ethical approval of the study protocols was obtained.

Results

Patients served in the Catalan national health system generally perceived that the three types of continuity of care were existent with a few elements of discontinuity identified in all study areas including the integrated health care networks. With regard to *continuity of clinical management across care levels*, patients reported that they had received the same diagnosis and treatment from physicians of the different care levels, without unnecessary repetitions of tests, and with timely referrals to the other care level when necessary. Furthermore, patients consistently perceived adequate waiting times for secondary care appointments after a referral in urgent cases, including exacerbations of COPD patients. Only a few patients across the areas identified elements of discontinuity, such as receiving different opinions on their treatment, some duplication of tests, missing referrals to secondary care when necessary or excessive waiting times for specific tests and non-urgent secondary care referrals. With reference to *continuity of information across care levels*, patients of both studies conducted in Catalonia generally perceived that clinical information was registered, transferred across levels via computer and up taken by the physicians; with the exception of one study area (Ciutat Vella in Barcelona), where information was perceived to be shared

only partially. Furthermore, some patients across the areas highlighted that specific information was not shared via computer and that some physicians, in particular though emergency and locum doctors, did not always consult the information stored in their records. Finally, with regard to *relational continuity*, most patients highlighted that they were usually seen by the same primary care physician over a longer period of time and only in rare occasions by locum doctors; however, COPD patients of some integrated health care network highlighted high turnover of primary care personnel. With reference to secondary care, numerous patients of both studies indicated inconsistencies; however, most patients did not find that to be a problem considering that all specialists were competent to treat their health problem and their clinical data was shared. Nearly all patients who perceived consistency of personnel developed an ongoing relationship with their physicians based on personal trust and the physician knowing them.

A number of factors influencing (dis)continuity of care were identified, which were classified into factors related to the healthcare system, the organizations and the physicians. With reference to the *healthcare system*, patients of both studies considered that the clear distribution of roles and responsibilities between primary and secondary care physicians enhanced the consistency in diagnosis and treatment and avoided incompatibilities of prescribed medication and the duplication of tests. Nevertheless, according to some patients, the 'gatekeeper system' could also extend waiting times or even fail to provide access to secondary care. With regard to the *health care organization*, the implemented care coordination mechanisms (electronic medical records, face-to-face meetings), mechanisms for informal communication (use of e-mail and telephone) and co-location of physicians in the primary care centre; which emerged in some study areas, were considered to positively influence the receipt of consistent treatment, the adequate information transfer and usage and the timeliness of secondary care referrals; whereas insufficient resources demonstrated by a shortage of doctors was considered to cause long waiting times for secondary care and insufficient uptake of clinical data. Concerning relational continuity, according to patients, the small size of the primary care centre in two study areas and an adequate appointment-making system favoured consistency of personnel; whereas the re-organization of patient lists distracted from it. Finally, in terms of influencing factors related to *physicians*, the primary care physician's technical competence favoured adequate and timely referrals to secondary care. Their willingness to collaborate influenced the uptake of information and avoided the duplication of tests and inconsistencies in treatment. The physician's adequate medical practice, as well as an effective patient-physician communication enhanced the development of an ongoing patient-doctor relationship based on trust and accumulated knowledge. The physician's commitment to patient care appeared to influence both the use of information and the development of trust.

Patients identified different consequences of all three types of continuity of care related to quality of care and, to a lesser extent, to health outcomes. In relation to *continuity of clinical management*, patients perceived that a lack of consistency of care and access

across levels resulted in an inadequate use of resources by duplicating visits, and produced feelings of anxiety and potential negative health effects when there were long waiting times for secondary care after a referral, which led to the patient seeking private health care. Concerning *continuity of information*, patients highlighted that the sharing of their clinical information across levels avoided duplication of medical tests and interventions, and the prescription of incompatible drugs. Moreover, patients did not need to store and carry test results to the physician of the other care level. Finally, regarding *relational continuity*, consistency of personnel was related by patients to fewer unnecessary referrals, no harmful modifications of the medication plan and duplication of tests. Furthermore, an ongoing relationship based on trust and accumulated knowledge was perceived to facilitate diagnose making, led to feelings of security and comfortableness and resulted in the patient being adherent to the treatment plan.

Conclusions

This thesis contributes to filling the existing knowledge gap on continuity of care by providing a better understanding of the phenomenon as perceived by healthcare users of the national health system of Catalonia. Results suggest that patients are able to perceive the three types of continuity of care by referring to concrete attributes of each dimension. The three types of continuity of care appeared to be interrelated; particularly continuity of information affecting continuity of clinical management, and relational continuity playing an important role by influencing continuity of clinical management and information. Patients generally perceive the existence of the three types of continuity of care; however also highlight some interruptions in all study areas. A number of factors influencing (dis)continuity of care were identified, related to the healthcare system, health care organization and physicians. Different consequences of all three types of continuity of care for quality of care and the patient's health emerged in the study findings. The identified elements of discontinuity serve to indicate where there is room for improvement, and the factors influencing continuity can offer valuable insights to managers and professionals of health care organizations in these and other contexts on where to direct their care coordination efforts; which supposedly would also enhance the patient's experience of a smooth trajectory along the care continuum.

RESUMEN

Introducción

La alta especialización en la provisión de la atención, los rápidos avances en la tecnología y la diversificación de los proveedores promueve que los pacientes sean atendidos por varios profesionales de diferentes disciplinas en organizaciones y servicios diferentes. Estas tendencias, junto con los cambios demográficos y epidemiológicos, hacen que el paciente, cada vez más, esté expuesto a una atención fragmentada. La atención fragmentada, o la atención coordinada insuficientemente entre los proveedores, pueden perjudicar al paciente, debido a la duplicación de pruebas diagnósticas, la poli-medicación inapropiada y los planes de tratamiento incompatibles. Los sistemas de salud y las organizaciones disponen de diferentes intervenciones que pueden implementar para facilitar la coordinación de servicios que se proveen a los individuos y la población, como por ejemplo la introducción de organizaciones sanitarias integradas. Estas organizaciones son definidas como un conjunto de proveedores de salud que ofrece una atención coordinada a través del continuo asistencial a una población determinada y se responsabiliza de los costes y resultados de salud de la población. Sus objetivos finales son la mejora de la eficiencia global, equidad en el acceso y la calidad de la atención, a través de la mejora de la coordinación y de la continuidad entre niveles asistenciales. La continuidad asistencial es la percepción del paciente sobre la coordinación de los servicios y se puede definir como el grado de coherencia y unión de las experiencias en la atención que percibe el usuario a lo largo del tiempo. Abarca tres tipos: la continuidad de gestión clínica y la continuidad de información entre niveles de atención y la continuidad de relación con el médico de atención primaria y el médico de atención especializada. En Cataluña (España), organizaciones sanitarias integradas emergieron como una respuesta a la diversidad de proveedores en la gestión de la atención primaria, secundaria y socio-sanitaria. No obstante, su desempeño ha sido analizado principalmente desde la perspectiva de los proveedores, es decir, en relación a la coordinación entre niveles asistenciales. Los estudios sobre la percepción de la continuidad asistencial, los factores que influyen y las consecuencias desde el punto de vista de los usuarios del sistema nacional de salud de Cataluña siguen siendo escasos.

Objetivo

Explorar la percepción del usuario sobre la continuidad entre niveles asistenciales en las diferentes áreas del sistema nacional de salud catalán, así como los factores que influyen y las consecuencias sobre la calidad de la atención, con la finalidad de contribuir a su mejora en el sistema de salud.

Métodos

La investigación consistió en tres estudios que abordan diferentes aspectos de la continuidad asistencial.

1) Análisis de la evidencia internacional sobre la continuidad asistencial desde la perspectiva del paciente, mediante una meta-síntesis de estudios cualitativos basada en la búsqueda bibliográfica en diferentes bases de datos electrónicas (Medline, Web of Science y Cochrane Library Plus). La estrategia de búsqueda incluyó la combinación de "continuidad asistencial" o términos relacionados, estudios cualitativos y la perspectiva del paciente. 25 estudios originales, publicados entre 1999 y 2009 que cumplieron con los criterios de inclusión fueron incluidos en la síntesis. Se realizó un análisis de contenido mediante la identificación de temas y categorías y la agregación de los resultados de los tres tipos de continuidad asistencial.

2) Análisis de la percepción de la continuidad asistencial de los pacientes con EPOC atendidos en cuatro organizaciones sanitarias integradas del sistema nacional de salud de Cataluña, mediante un estudio de caso múltiple de los pacientes con EPOC. Se seleccionó una muestra teórica en dos etapas: (i) cuatro organizaciones sanitarias integradas, (ii) dos casos de estudio de cada organización que incluían un paciente con EPOC, su médico de atención primaria, su neumólogo y su historia clínica. La información fue recogida mediante entrevistas individuales semiestructuradas con los pacientes y sus médicos y la revisión de las historias clínicas. Todas las entrevistas fueron grabadas y transcritas literalmente. Se llevó a cabo un análisis temático de contenido, segmentando la información por organización y caso, con una triangulación de fuentes y la participación de diferentes analistas.

3) Análisis de la continuidad asistencial en las diferentes áreas sanitarias del sistema nacional de salud catalán, enfocando el análisis en los tres tipos de continuidad asistencial, los factores que influyen y las consecuencias en la calidad de la atención. Se seleccionó una muestra teórica en dos etapas: (i) contexto de estudio: tres áreas sanitarias que representan la diversidad de modelos de gestión para la provisión de los servicios sanitarios y (ii) los usuarios de los servicios sanitarios. Se realizaron entrevistas individuales semiestructuradas con los usuarios de los servicios sanitarios (de 14 a 18 por área) hasta alcanzar la saturación de la información. Todas las entrevistas fueron grabadas y transcritas textualmente. Se llevó a cabo un análisis de contenido temático, segmentando la información por área de estudio, con una generación mixta de categorías y la participación de diferentes analistas para garantizar la calidad de los resultados. Se obtuvo la aprobación ética de los protocolos de estudio.

Resultados

En general, los pacientes atendidos en el sistema nacional de salud catalán percibieron la existencia de los tres tipos de continuidad asistencial con algunos elementos de discontinuidad identificados en todas las áreas y organizaciones

sanitarias integradas de estudio. Con relación a la *continuidad de la gestión clínica entre niveles asistenciales*, los pacientes percibieron que habían recibido el mismo diagnóstico y tratamiento por los médicos de los diferentes niveles asistenciales, sin repeticiones innecesarias de pruebas, y con las derivaciones oportunas al otro nivel de atención cuando era necesario. Además, los pacientes señalaron de manera consistente tiempos de espera adecuados a la atención especializada en casos urgentes, incluidos las exacerbaciones de los pacientes con EPOC, y después de una derivación. Sólo unos pocos pacientes de todas las áreas identificaron elementos de discontinuidad, por ejemplo las diferentes opiniones sobre su tratamiento, algunas duplicaciones de pruebas, falta de derivaciones a la atención especializada cuando las necesitaban y tiempos de espera excesivos para algunas pruebas específicas y la derivación a la atención especializada no urgente. En referencia a la *continuidad de la información entre niveles asistenciales*, los pacientes de ambos estudios realizados en Cataluña, en general, percibieron que la información clínica se registró, fue transferida entre niveles mediante el ordenador y utilizada por los médicos, con la excepción de un área de estudio (Ciutat Vella en Barcelona), donde se percibió que la información fue compartida parcialmente. Además, algunos pacientes de todas las áreas destacaron que alguna información no fue compartida a través del ordenador y que algunos médicos, especialmente los médicos de urgencias y los médicos suplentes, no siempre consultaron la información de la historia clínica. Finalmente, en cuanto a la *continuidad de relación*, la mayoría de los pacientes señalaron que en general fueron atendidos por el mismo médico de atención primaria durante un largo periodo y por médicos suplentes en algunas ocasiones. Sin embargo, los pacientes con EPOC de algunas organizaciones sanitarias integradas destacaron una alta rotación del personal de atención primaria. Con referencia a la atención especializada, numerosos pacientes de ambos estudios señalaron inconsistencias; aunque muchos pacientes no las identificaron como un problema al considerar que todos los médicos de la atención especializada eran competentes para tratar su problema de salud y que se compartía la información clínica. Casi todos los pacientes que percibieron una consistencia del personal también desarrollaron una relación continua basada en la confianza con los médicos y el conocimiento acumulado.

Se identificaron varios factores que influyen en (la falta de) la continuidad asistencial, que se clasificaron en los factores relacionados con el sistema de salud, las organizaciones y los médicos. En relación con el *sistema de salud*, los pacientes de ambos estudios consideraron que la clara distribución de roles y responsabilidades entre los médicos de atención primaria y especializada favoreció la consistencia del diagnóstico y tratamiento y evitó incompatibilidades en la medicación prescrita y duplicaciones de pruebas. Sin embargo, según algunos pacientes, la función de puerta de entrada del médico de atención primaria podría también extender los tiempos de espera o incluso impedir el acceso a la atención especializada. Con respecto a las *organizaciones sanitarias*, los usuarios consideraron que los mecanismos de coordinación implementados (historia clínica compartida, reuniones presenciales), los

mecanismos de comunicación informal (uso del correo electrónico y teléfono) y la co-localización de los médicos en el centro de atención primaria, que emergieron sólo en algunas áreas de estudio, influyeron positivamente en la recepción de un tratamiento consistente, la transferencia y uso de información adecuada y las derivaciones oportunas a la atención especializada. Por otro lado consideraron que los insuficientes recursos disponibles, evidenciados por la falta de médicos, causó largos tiempos de espera para la atención secundaria y un uso insuficiente de la información clínica. En cuanto a la continuidad de relación, según los pacientes, los pequeños centros de atención primaria en dos áreas de estudio y un sistema para la obtención de citas adecuado favorecen la consistencia del personal; mientras que la re-organización de listas de pacientes la dificultan. Por último, en relación con los factores relacionados con los *médicos*, la competencia técnica del médico de atención primaria promovió derivaciones adecuadas y oportunas a la atención secundaria. Consideraron que la disposición del médico a colaborar influyó en el uso de la información y evitó duplicaciones de pruebas e inconsistencias en el tratamiento. La práctica médica adecuada, así como una comunicación médico-paciente efectiva favorecieron el desarrollo de una relación médico-paciente basada en la confianza y el conocimiento acumulado mutuo. El compromiso del médico en el cuidado del paciente pareció influir tanto en el uso de la información como en el establecimiento de una confianza mutua.

Los pacientes identificaron diferentes consecuencias de los tres tipos de continuidad asistencial relacionadas con la calidad de la atención y, en menor medida, con los resultados de salud. Respecto con la *continuidad de la gestión clínica*, los pacientes percibieron que la falta de consistencia de la atención y de acceso entre niveles resultó en un uso inadecuado de recursos, debido a que se duplicaron visitas. Además produjo angustia y posibles efectos negativos para la salud, cuando se dieron largos tiempos de espera a la atención especializada después de una derivación, que llevó a que el paciente buscara atención médica privada. En cuanto a la *continuidad de la información*, los pacientes destacaron que el intercambio de la información clínica entre niveles evitó la duplicación de pruebas e intervenciones médicas y la prescripción de medicamentos incompatibles. Además, los pacientes no necesitaban guardar y llevar los resultados de las pruebas al médico del otro nivel de atención. Por último, en cuanto a la *continuidad de relación*, los pacientes relacionaron la consistencia del personal con menos derivaciones innecesarias, sin modificaciones en el plan de tratamiento que pudieran perjudicar al paciente ni duplicaciones de pruebas. Además, percibieron que una relación continúa basada en la confianza y el conocimiento acumulado facilitó el diagnóstico y dio lugar a una sensación de seguridad y comodidad así como que el paciente siguiera adecuadamente el plan de tratamiento.

Conclusiones

Esta tesis contribuye al conocimiento sobre la continuidad asistencial, un tema escasamente analizado, mediante una mejor comprensión del fenómeno percibido por los usuarios de los servicios sanitarios del sistema nacional de salud de Cataluña. Los

resultados sugieren que el paciente es capaz de percibir los tres tipos de continuidad asistencial refiriéndose a atributos concretos de cada dimensión. Los tres tipos de continuidad asistencial parecen estar relacionados entre sí; particularmente la continuidad de información afecta a la continuidad de gestión clínica, y la continuidad de relación juega un papel importante al influir en la continuidad de gestión clínica y de información. Los pacientes en general perciben la existencia de los tres tipos de continuidad asistencial. Sin embargo, también señalan algunas interrupciones en la continuidad en todas las áreas de estudio. Se identificaron varios factores que influyen en la (dis)continuidad asistencial, relacionados con el sistema de salud, las organizaciones sanitarias y los médicos. Como resultado del estudio, se identificaron diferentes consecuencias de los tres tipos de continuidad asistencial en la calidad de la atención y la salud del paciente. Los elementos de discontinuidad identificados sirven para indicar donde hay margen de mejora, y los factores que influyen en la continuidad pueden ofrecer información valiosa a los directivos y profesionales de las organizaciones sanitarias en estos y otros contextos sobre dónde dirigir sus esfuerzos de coordinación asistencial; que supuestamente también mejoraría la experiencia de una trayectoria fluida a lo largo del continuo asistencial del paciente.

RESUM

Introducció

L'alta especialització en la provisió de l'atenció, els ràpids avanços en la tecnologia i la diversificació dels proveïdors promou que els pacients siguin atesos per diversos professionals de diferents disciplines en organitzacions i serveis diferents. Aquestes tendències, juntament amb els canvis demogràfics i epidemiològics, fan que el pacient, cada vegada més, estigui exposat a una atenció fragmentada. L'atenció fragmentada, o l'atenció coordinada insuficientment entre els proveïdors, poden perjudicar al pacient, a causa de la duplicació de proves diagnòstiques, la poli-medicació inapropiada i els plans de tractament incompatibles. Els sistemes de salut i les organitzacions disposen de diferents intervencions que poden implementar per facilitar la coordinació de serveis que es proveeixen als individus i la població, com ara la introducció d'organitzacions sanitàries integrades. Aquestes organitzacions són definides com un conjunt de proveïdors de salut que ofereix una atenció coordinada a través del continu assistencial a una població determinada i es responsabilitza dels costos i resultats de salut de la població. Els seus objectius finals són la millora de l'eficiència global, equitat en l'accés i la qualitat de l'atenció, a través de la millora de la coordinació i de la continuïtat entre nivells assistencials. La continuïtat assistencial és la percepció del pacient sobre la coordinació dels serveis i es pot definir com el grau de coherència i unió de les experiències en l'atenció que percep l'usuari al llarg del temps. Abasta tres tipus: la continuïtat de gestió clínica i la continuïtat d'informació entre nivells d'atenció i la continuïtat de relació amb el metge d'atenció primària i el metge d'atenció especialitzada. A Catalunya (Espanya), organitzacions sanitàries integrades van sorgir com una resposta a la diversitat de proveïdors en la gestió de l'atenció primària, secundària i sociosanitària. No obstant això, el seu acompliment ha estat analitzat principalment des de la perspectiva dels proveïdors, és a dir, en relació a la coordinació entre nivells assistencials. Els estudis sobre la percepció de la continuïtat assistencial, els factors que influeixen i les conseqüències des del punt de vista dels usuaris del sistema nacional de salut de Catalunya segueixen sent escassos.

Objectiu

Explorar la percepció de l'usuari sobre la continuïtat entre nivells assistencials en les diferents àrees del sistema nacional de salut català, així com els factors que influeixen i les conseqüències sobre la qualitat de l'atenció, amb la finalitat de contribuir a la seva millora en el sistema de salut.

Mètodes

La investigació ha consistit en tres estudis que aborden diferents aspectes de la continuïtat assistencial.

1) Anàlisi de l'evidència internacional sobre la continuïtat assistencial des de la perspectiva del pacient, mitjançant una meta-síntesi d'estudis qualitius basada en la recerca bibliogràfica en diferents bases de dades electròniques (Medline, Web of Science i Cochrane Library Plus). L'estratègia de recerca va incloure la combinació de "continuïtat assistencial" o termes relacionats, estudis qualitius i la perspectiva del pacient. 25 estudis originals, publicats entre 1999 i 2009 que complien amb els criteris d'inclusió van ser inclosos en la síntesi. Es va realitzar una anàlisi de contingut mitjançant la identificació de temes i categories i l'agregació dels resultats dels tres tipus de continuïtat assistencial.

2) Anàlisi de la percepció de la continuïtat assistencial dels pacients amb MPOC atesos en quatre organitzacions sanitàries integrades del sistema nacional de salut de Catalunya, mitjançant un estudi de cas múltiple dels pacients amb MPOC. Es va seleccionar una mostra teòrica en dues etapes: (i) quatre organitzacions sanitàries integrades, (ii) dos casos d'estudi de cada organització que inclouen un pacient amb MPOC, el seu metge d'atenció primària, el seu pneumòleg i la seva història clínica. La informació va ser recollida mitjançant entrevistes individuals semiestructurades amb els pacients i els seus metges i la revisió de les històries clíniques. Totes les entrevistes van ser gravades i transcrites literalment. Es va dur a terme una anàlisi temàtica de contingut, segmentant la informació per organització i cas, amb una triangulació de fonts i la participació de diferents analistes.

3) Anàlisi de la continuïtat assistencial en les diferents àrees sanitàries del sistema nacional de salut català, enfocant l'anàlisi en els tres tipus de continuïtat assistencial, els factors que influeixen i les seves conseqüències en la qualitat de l'atenció. Es va seleccionar una mostra teòrica en dues etapes: (i) context d'estudi: tres àrees sanitàries que representen la diversitat de models de gestió per a la provisió dels serveis sanitaris i (ii) els usuaris dels serveis sanitaris. Es van realitzar entrevistes individuals semiestructurades amb els usuaris dels serveis sanitaris (de 14 a 18 per àrea) fins a arribar a la saturació de la informació. Totes les entrevistes van ser gravades i transcrites textualment. Es va dur a terme una anàlisi de contingut temàtic, segmentant la informació per àrea d'estudi, amb una generació mixta de categories i la participació de diferents analistes per garantir la qualitat dels resultats. Es va obtenir l'aprovació ètica dels protocols d'estudi.

Resultats

En general, els pacients atesos en el sistema nacional de salut català van percebre l'existència dels tres tipus de continuïtat assistencial amb alguns elements de discontinuïtat identificats en totes les àrees i organitzacions sanitàries integrades d'estudi. En relació amb la continuïtat de la gestió clínica entre nivells assistencials, els pacients van percebre que havien rebut el mateix diagnòstic i tractament pels metges dels diferents nivells assistencials, sense repeticions innecessàries de proves, i amb les derivacions oportunes a l'altre nivell d'atenció quan era necessari. A més, els pacients van assenyalar de manera consistent temps d'espera adequats a l'atenció

especialitzada en casos urgents, inclosos les exacerbacions dels pacients amb MPOC, i després d'una derivació. Només uns pocs pacients de totes les àrees van identificar elements de discontinuïtat, per exemple les diferents opinions sobre el seu tractament, algunes duplicacions de proves, manca de derivacions a l'atenció especialitzada quan les necessitaven i temps d'espera excessius per a algunes proves específiques i la derivació a l'atenció especialitzada no urgent. Pel que fa a la continuïtat de la informació entre nivells assistencials, els pacients d'ambdós estudis realitzats a Catalunya, en general, van percebre que la informació clínica es va registrar, va ser transferida entre nivells mitjançant l'ordinador i utilitzada pels metges, amb l'excepció d'una àrea de estudi (Ciutat Vella a Barcelona), on es va percebre que la informació va ser compartida parcialment. A més, alguns pacients de totes les àrees han destacat que alguna informació no va ser compartida a través de l'ordinador i que alguns metges, especialment els metges d'urgències i els metges suplents, no sempre van consultar la informació de la història clínica. Finalment, pel que fa a la continuïtat de relació, la majoria dels pacients van assenyalar que en general van ser atesos pel mateix metge d'atenció primària durant un llarg període i per metges suplents en algunes ocasions. No obstant això, els pacients amb MPOC d'algunes organitzacions sanitàries integrades destaquen una alta rotació del personal d'atenció primària. Amb referència a l'atenció especialitzada, nombrosos pacients d'ambdós estudis van assenyalar inconsistències; encara que molts pacients no les van identificar com un problema en considerar que tots els metges de l'atenció especialitzada eren competents per tractar el seu problema de salut i que es compartia la informació clínica. Gairebé tots els pacients que van percebre una consistència del personal també van desenvolupar una relació contínua basada en la confiança amb els metges i el coneixement acumulat.

Es van identificar diversos factors que influeixen en (la manca de) la continuïtat assistencial, que es van classificar en els factors relacionats amb el sistema de salut, les organitzacions i els metges. En relació amb el sistema de salut, els pacients d'ambdós estudis van considerar que la clara distribució de rols i responsabilitats entre els metges d'atenció primària i especialitzada va afavorir la consistència del diagnòstic i tractament i va evitar incompatibilitats en la medicació prescrita i duplicacions de proves. No obstant això, segons alguns pacients, la funció de porta d'entrada del metge d'atenció primària podria també estendre els temps d'espera o fins i tot impedir l'accés a l'atenció especialitzada. Pel que fa a les organitzacions sanitàries, els usuaris van considerar que els mecanismes de coordinació implementats (història clínica compartida, reunions presencials), els mecanismes de comunicació informal (ús del correu electrònic i telèfon) i la co-localització dels metges al centre d'atenció primària, que van emergir només en algunes àrees d'estudi, van influir positivament en la recepció d'un tractament consistent, la transferència i ús d'informació adequada i les derivacions oportunes a l'atenció especialitzada. D'altra banda van considerar que els insuficients els recursos disponibles, evidenciats per la falta de metges, va causar llargs temps d'espera per a l'atenció secundària i un ús insuficient de la informació

clínica. Pel que fa a la continuïtat de relació, segons els pacients, els petits centres d'atenció primària en dues àrees d'estudi i un sistema per a l'obtenció de cites adequat afavoreixen la consistència del personal; mentre que la re-organització de llistes de pacients la dificulten. Finalment, en relació amb els factors relacionats amb els metges, la competència tècnica del metge d'atenció primària va promoure derivacions adequades i oportunes a l'atenció secundària. Van considerar que la disposició del metge a col·laborar va influir en l'ús de la informació i va evitar duplicacions de proves i inconsistències en el tractament. La pràctica mèdica adequada, així com una comunicació metge-pacient efectiva va afavorir el desenvolupament d'una relació metge-pacient basada en la confiança i el coneixement acumulat mutu. El compromís del metge en la cura del pacient sembla que va influir tant en l'ús de la informació com en l'establiment d'una confiança mútua.

Els pacients identifiquen diferents conseqüències dels tres tipus de continuïtat assistencial relacionades amb la qualitat de l'atenció i, en menor mesura, amb els resultats de salut. Respecte a la continuïtat de la gestió clínica, els pacients van percebre que la manca de consistència de l'atenció i d'accés entre nivells va resultar en un ús inadequat de recursos, pel fet que es van duplicar visites. A més va produir angoixa i possibles efectes negatius per a la salut, quan es van donar llargs temps d'espera a l'atenció especialitzada després d'una derivació, que va portar al fet que el pacient busqués atenció mèdica privada. Pel que fa a la continuïtat de la informació, els pacients van destacar que l'intercanvi de la informació clínica entre nivells va evitar la duplicació de proves i intervencions mèdiques i la prescripció de medicaments incompatibles. A més, els pacients no necessitaven guardar i portar els resultats de les proves al metge de l'altre nivell d'atenció. Finalment, pel que fa a la continuïtat de relació, els pacients van relacionar la consistència del personal amb menys derivacions innecessàries, sense modificacions en el pla de tractament que poguessin perjudicar el pacient ni duplicacions de proves. A més, van percebre que una relació continua basada en la confiança i el coneixement acumulat va facilitar el diagnòstic i va donar lloc a una sensació de seguretat i comoditat així com que el pacient seguís adequadament el pla de tractament.

Conclusions

Aquesta tesi contribueix al coneixement sobre la continuïtat assistencial, un tema escassament analitzat, mitjançant una millor comprensió del fenomen percebut pels usuaris dels serveis sanitaris del sistema nacional de salut de Catalunya. Els resultats suggereixen que el pacient és capaç de percebre els tres tipus de continuïtat assistencial referint-se a atributs concrets de cada dimensió. Els tres tipus de continuïtat assistencial semblen estar relacionats entre si; particularment la continuïtat d'informació afecta la continuïtat de gestió clínica, i la continuïtat de relació juga un paper important en influir en la continuïtat de gestió clínica i d'informació. Els pacients en general perceben l'existència dels tres tipus de continuïtat assistencial. No obstant això, també assenyalen algunes interrupcions en la continuïtat en totes les àrees d'estudi. Es van identificar diversos factors que influeixen en la (dis) continuïtat

assistencial, relacionats amb el sistema de salut, les organitzacions sanitàries i els metges. Com a resultat de l'estudi, es van identificar diferents conseqüències dels tres tipus de continuïtat assistencial en la qualitat de l'atenció i la salut del pacient. Els elements de discontinuïtat identificats serveixen per indicar on hi ha marge de millora, i els factors que influeixen en la continuïtat poden oferir informació valuosa als directius i professionals de les organitzacions sanitàries en aquests i altres contextos sobre on dirigir els seus esforços de coordinació assistencial; que suposadament també milloraria l'experiència d'una trajectòria fluïda al llarg del continu assistencial del pacient.

I. INTRODUCTION

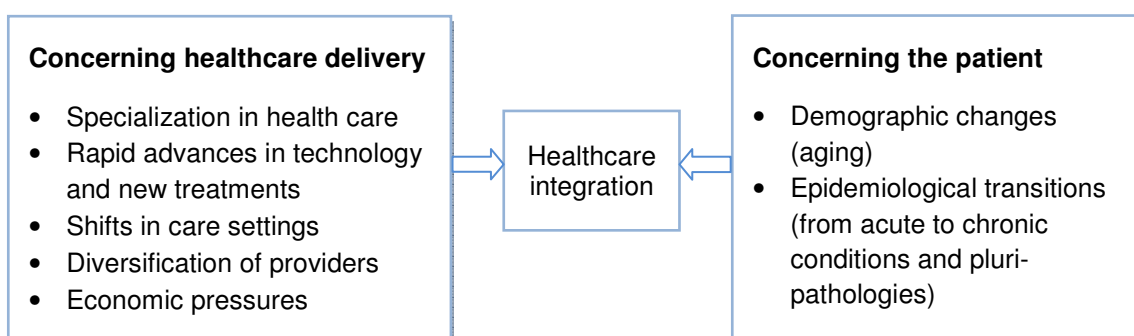
1. Care integration

1.1. The need for integrating healthcare services

Integrated care has become an international healthcare buzzword, attracting considerable attention in many countries since being considered a means to develop more efficient health systems that deliver higher quality care [1]. The need for better integrated care is not only been highlighted in the growing international literature but has also become a priority area in different resolutions of international organisms for improving health systems in Europe and other continents for example by the World Health Organization (WHO), that encourages the provision of comprehensive primary health care services that are integrated with other level of care (62nd World Health Assembly [2]); the Pan American Health Organization (PAHO), that promotes the implementation of integrated health care networks [3] or the European Commission, that aims at optimizing the efficiency and effectiveness of healthcare systems and reducing inequalities in Europe via integrated care [4]. Although all organisms refer to the concept of integrated care, their understanding of what the concept embraces and the manner how to implement the changes is limitedly defined. Here, we consider care integration to be the highest degree of care coordination [5], which can be defined as the harmonious connection of the different services needed to provide care to a patient throughout the care continuum in order to achieve a common objective without conflicts [5;6].

Different forces are highlighted in the literature that give rise to the need for improving health services towards care integration, which relate to the delivery of health care on the one hand and the patient on the other hand [7] (Figure 1). With reference to healthcare delivery, specialization and sub-specialization in health care is considered to lead to increased complexity of the care provided and to the risk of care fragmentation [8], as well as rapid advances in technology, new treatments and shifts in care from institutional to outpatient and home settings [9]. Competition and privatization have resulted in fragmented healthcare provision due to diversification of providers that further challenge the achievement of care integration [8]. The economic constraints introduced in the context of the financial crisis have accentuated the need for integrating care given its potential for achieving a more efficient use of health resources [1;10]. Underlying forces concerning the patient embrace demographic and epidemiological changes, such as the trend to a rapid ageing population and the shift from acute diseases to chronic conditions and multi-morbidities. Providing seamless care to those patients is seen to be particularly challenging because they receive care from several professionals of different disciplines in various settings and institutions, hence are exposed to fragmented care delivery [9;11].

Figure 1. Main driving forces for health services towards healthcare integration



Source: Adapted from Gröne and Garcia-Barbero [7]

Insufficiently coordinated health care has been suggested to be one of the key causes of poor quality health care [12;13]; due to duplication of diagnostic tests, inappropriate polypharmacy and conflicting care plans [12]. Problems are most likely to arise at key interfaces between primary and secondary care and between specialities [8]; within the boundary of one organization or facility (such as hospitals) or across the boundaries (when a patient is transferred physically from one facility to another, but also when professionals in one organisation need to coordinate the patient's treatment, for example by obtaining test results held by another organization) [14].

1.2. Integrated health care networks and other care coordination interventions

Health systems and organizations may introduce an array of interventions to facilitate the continuous and coordinated delivery of services to individuals and populations, which can be categorized into the different levels within a healthcare system (macro, meso and micro) [15]. The best outcomes are achieved when interventions of all three levels are introduced simultaneously [16].

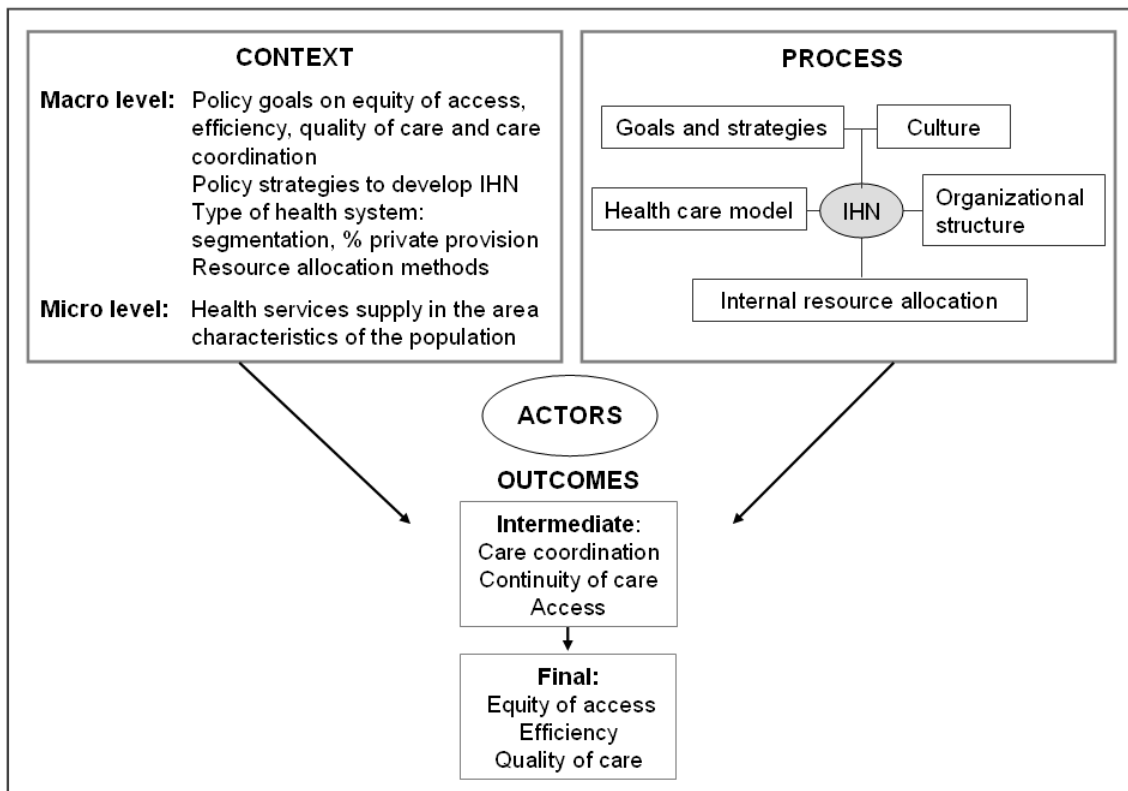
- *Macro level (health system)*: policies and regulatory mechanisms to develop integrated health care organizations; integrated purchasing strategy, including capitation payment, that fall under the responsibility of health authorities and regulatory bodies [16-18];
- *Meso level (organization)*: health organizations' strategic plans; functional integration and coordination mechanisms for managerial functions (e.g. integrated management strategies, shared management committee) to be developed and implemented by health managers [16-18];
- *Micro level (clinical management)*: the introduction of a single mechanism (e.g., integrated information system, clinical guidelines and pathways, referral mechanisms) or a combination of coordination mechanisms in a program (e.g. disease and case management programs), to be developed and implemented by health managers and professionals [16-18].

At the macro and the meso level, the implementation of integrated health care networks might be highlighted which has been endorsed by national governments of

low and middle-income countries [19-21] but also in Europe, the USA [22-24] and Canada [25;26] as well as by multilateral organizations, such as the World Health Organization [2], the Pan American Health Organization [3] or the World Bank [27]. Integrated health care networks (also called integrated health services delivery networks [19] or integrated delivery networks [28], integrated delivery systems [29]) can be defined as networks that provide or arrange to provide a coordinated continuum of health services to a defined population and are willing to be held clinically and fiscally accountable for the outcomes and health status of the population [5]. Their ultimate objectives are to improve global system efficiency, equity of access and quality of care by means of enhancing access, coordination and continuity of care [18]. Integrated health care networks can be characterised by their integration width (number of different types of services provided by the network across the care continuum), integration depth (extent to which a given service is provided at multiple operating units within a network), geographic concentration of services, level of internal production of services and their inter-organisational relationship [5].

The performance of integrated health care networks can be analysed by applying the conceptual framework developed by Vázquez et al. [18;30] based on a review of the literature. The framework suggests the analysis of their performance with regard to their final outcomes (equity of access, efficiency, and quality of care) but also their intermediate outcomes (care coordination, continuity of care and access) and taking into account the internal processes developed by the networks to achieve their objectives and the contexts in which the networks perform [18] (Figure 2). Internal processes refer to several organisational elements that are critical for care integration to exist, e.g. an organic structure with mechanisms that enable efficient communication between different health professionals [31], a common culture and leadership with values oriented toward teamwork, collaboration, and performance [32] or an internal resource allocation system that aligns the incentives of health services to the global objectives of the network [23]. Contextual elements embrace, for example, health policy goals regarding the development of networks, characteristics of the ascribed population, type of health system (entitlements to health care, benefit packages and access conditions) or resource allocation methods [33].

Figure 2. Framework for analysing integrated health care networks



Source: Adapted from Vázquez et al. 2009 [18;30]

IHN: Integrated health care networks

2. Continuity of care

2.1. Conceptualizing continuity of care

2.1.1. Continuity of care and related concepts

Continuity of care, care coordination and integration are terms often used interchangeably in the literature to refer to the same idea: the connection of the health care the patient receives from different providers [34]. Nevertheless, these terms have slightly different meanings [11;35;36]. The need for clarifying boundaries between related concepts and standardizing terms has been highlighted because existing ambiguities are considered to partly explain the encountered difficulties to share experiences, prepare proposals for action and to evaluate advances in these areas [3].

Care coordination can be defined as the harmonious connection of the different health services needed to provide care to a patient throughout the care continuum in order to achieve a common objective without conflicts [5;6]. Three interrelated types can be distinguished: information coordination or the transfer and use of the patient clinical information needed to coordinate activities between providers; clinical management coordination or the provision of care in a sequential and complementary way [9], and administrative coordination, or the coordination of patient access across the continuum

of services according to their needs, an aspect less frequently conceptualised by scholars [21]. *Integrated care* is considered the highest degree of coordination [5] and was defined by the Pan American Health Organization [3] as the management and delivery of health services through the different levels and sites of care within the health system and according to the patients' needs. Finally, *continuity of care*, following the framework by Reid et al. [9], is defined as how one patient experiences care over time as coherent and linked; thus is the patient's perception of the coordination of services [9;37].

2.1.2. The evolution of the conceptual framework

The term continuity of care initially appeared in the 1950s when the first researchers in general practice were trying to explore and define their discipline [36]. The concept, at this time, focused on having a personal care provider over time [36], referring to *longitudinality*, which can be defined as having a regular source of care over time regardless of the nature of the problem [38;39]. Later on, the focus shifted from having a personal provider to care that was uninterrupted and coordinated, i.e. continuity as the means by which separate parts of an episode of illness are joined [38;39]. It could be interpreted that this definition refers to the analysis of continuity *across care levels*. In the 1990s, continuity of care was defined as individuals using their primary source of care over time for most of their health care needs, and was considered to be one of the main functions of good primary care together with first-contact, comprehensive and coordinated care across levels [40;41]. Since the early 2000, continuity of care is seen as the result, over time, of good information flow, good interpersonal skills by professionals and good coordination between providers across the care levels, which is preferably measured from the patient's point of view [9].

In the decade of 2000, different multidimensional models for the analysis of continuity of health care emerged. The first model was developed by the English National Institute for Health Research (NIHR) Service Delivery and Organisation (SDO) in 2001 by Freeman et al. [42] was based on an extensive literature review and included five types of continuity of health care: *continuity of information* (information transfer following the patient), *cross-boundary and team continuity* (communication between professionals and services across care levels and with patients), *flexible continuity* (adjustment of care to the needs of the individual over time), *longitudinal continuity* (receipt of care from a few professionals as possible), *relational or personal continuity* (establishment and maintenance of a therapeutic relationship with one or more named professionals). The authors simplified the concept in 2006 by describing three major types [43] that coincided with the types identified by Reid et al. [9] and Haggerty et al. [37] in 2002, who also developed the conceptual model on the basis of a literature review and expert discussions including: *management continuity*, *informational continuity* and *relational continuity* (explained with more detail in the next chapter). In the primary care literature, relational continuity is often termed *provider continuity*, referring to the patient's perception of the relationship with a single physician [9], and in

the mental health literature, with the whole team who is responsible for patients in both inpatient and outpatient settings [44]. Two core elements that form the base for understanding its three types were added, which is care experienced by an individual and received over time [9]. In 2009, Wierdsma et al. considered the need to include a fourth type, *contact continuity*, for the study of continuity of care in patients with mental conditions, that referred to mental health organization having regular contact with the patient [45]. This type was mentioned in the preceding model [37], also in relation to mental health, however, being considered a feature of relational continuity rather than an additional type itself. Finally, the model by Saultz et al. [46] developed in the United States and based on a literature review on primary care defined continuity as a hierarchical concept consisting of three types, with increasing complexity: *interpersonal continuity* (ongoing patient-provider relationship characterized by personal trust and responsibility), *longitudinal continuity* (regular source of care) and *informational continuity* (access to comprehensive information about the patient's previous health care encounters by each provider caring for the patient). The first two types related to relational continuity as defined by Reid et al. [9]; management continuity seemed not to be included in this concept. With regard to informational continuity, although not explicitly mentioned, it could be assumed that Saultz et al. [46] also referred to continuity *across care levels* given that they focused on all health care professionals involved in the patient care communicating with each other.

Even though the conceptualization of continuity of care is been ongoing for some decades, there is no overall accepted model with clearly defined types; and there is still a lack of clarity and consensus on what continuity of care exactly means [47;48]. Unclear definitions might lead to difficulties in identifying and comparing literature on continuity of care, in delivering the continuity of care users need [48] and in determining its contribution of continuity to quality care [47].

2.1.3. Continuity preferably measured from the patient's perspective

The multidimensional models developed various definitions of continuity of care. Freeman et al. [42] defined continuity of care as 'the experience of a coordinated and smooth progression of care from the patient's point of view'; which is similar to the definition by Reid et al. [9]: continuity of care is 'the patient's experience of care as connected and coherent over time'. Lately, the Pan American Health Organization adapted Reid et al.'s definition [9] to 'the degree to which a series of discrete health care events is experienced by people as coherent and interconnected over time, and consistent with their health needs and preferences' [3;19]. All definitions coincide in that the concept refers to the perception and experience of an individual patient or service user; in contrast to the providers' perspective which would be the coordination of care [3;9;42],

Although it has been postulated that continuity should preferably be analysed from the patient's perspective [49], some researchers considered that specific aspects were less salient to health care users [43;50]; thus were questioning if they can actually perceive

coordinated care with its complex dimensions [51]. Nevertheless, recent literature suggests that patients notice the mechanisms of clinical collaboration set up between organizations [52] and can evaluate the effectiveness of initiatives or introduced mechanisms for better care coordination ('how well is care connected?') [49]. Thus, the analysis of continuity of care from the patient's perspective should enable to understand the relationship between the efforts made by the organizations to coordinate services and the continuity of care actually delivered to the patients - i.e. the extent to which they succeed in the delivery of coordinated care according to the patient's perception [53]. Furthermore, some authors argue that only patients can provide a global picture of the care received since they experience services along the continuum of care [54] and first-hand from multiple providers, (i.e. only the patient was present in both the primary care physician's and the specialist's office) [55].

Numerous recent literature suggests that patients particularly noticed when coordination of clinical management and information was absent, e.g. by highlighting the receipt of conflicting information about their medical history and care plans, insufficient communication between providers, disagreements on appropriate care and services delivered by physician of the different care levels and inadequate transitions between settings [54;56-58]. It was thus argued that patients can assess failures and gaps in the coordination and identify elements of lack of coordination in their health organizations [54].

Finally, seeking the patient's perspective can provide a better understanding of their care needs [49], which might differ according to individual factors, health condition and care trajectories, as well as care setting and service provision [48]. The analysis of patients' perceived needs might embrace question such as when and why they appreciate or actively chose discontinuity, for example, by welcoming new staff with greater skills [48] or seeking a second opinion [48;59], which situates them in a better position to compare physicians' performances [59] or simply not attending a scheduled appointment [60]. Being aware of the patient's care needs will allow for tailoring health services to the individual patient [49].

2.1.4. The conceptual framework elaborated by Reid et al.

The continuity of health care concept by Reid et al., based on an extensive multidisciplinary literature review and expert meetings, was first published in their report for the Canadian Health Service Research Foundation in 2002 [9] and one year later in a short research article [37]. Continuity of care was first defined in the report as 'how one patient experiences care over time as coherent and linked' [9] and then modified to 'continuity of care is the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context' [37]. In other word, continuity of care is how an individual patient experience the coordination of services between providers [9;37] and is the result of adequate access to care, good information flow and uptake, good coordination of care between providers to maintain care consistency and the

physician's good interpersonal skills to develop an ongoing relationship based on trust and mutual understanding [9]. Their concept is defined by two central elements: continuity of care experienced by an individual patient and received over time [37]. These elements form the base for the understanding of its three major types of continuity of care, each of which is characterized by two dimensions:

Management continuity is defined as the patient's perception of the degree to which health services are delivered in a coherent and complementary manner, in order to achieve health goals [9;37]. *Consistency of care*, its first dimension, is the patient's perception that treatment plans and objectives are coherent between the health professionals of different care levels. *Flexibility*, the second dimension, is the patient's perception that care plans are adapted to their specific needs, circumstances and values [9].

Informational continuity refers to the patient's perception of the availability and use of information of the patient's medical history and personal circumstances to make current care appropriate for each individual [9;37]. The *transfer and use of information*, the first dimension, relates to the patient's perception that patient information is transferred from one professional to another to bridge separate elements of care over time. *Accumulated knowledge*, the second dimension, refers to the patient's perception of the professionals' knowledge of their values, preferences, and social context and support mechanisms, to ensure that services are responsive to their needs [9].

Relational continuity is defined as the patient's perception of an ongoing relationship with one or more providers spanning different health care episodes [9;37]. The *ongoing patient-provider relationship*, its first dimension, relates to the patient's perception of the interpersonal relationship with the professional that is based on a sense of affiliation, trust, mutual understanding, patient loyalty and the professionals' sustained sense of responsibility toward the patient. *Consistency of personnel*, the second dimension, refers to the patient's perception of consistently seeing the same professionals, even in settings where there is little expectations of establishing long-term relationships, such as in acute care [9].

Whereas management and informational continuity refer to result of the interaction between providers – thus can be analysed within and across levels of care – relational continuity relates to the ongoing relationship between the patient and the professional [9], usually with the primary care professional [9;54], and hence can only be analysed in each care level separately.

Reid et al.'s [9] concept was used in a series of qualitative (e.g. Cowie et al. 2009; Nair et al. 2005; Nazareth et al. 2008) and quantitative studies (e.g. Aller et al. 2012; Uijen et al. 2011) to analyse the patient's perception of coordinated care. Nevertheless, a few limitations of the framework should be considered, as it is based on a literature review and consultations with researchers and policy makers; which did not include the patients' opinions. Furthermore, the interrelation of types and dimensions was mentioned, however, not further analysed which would allow for obtaining a better

understanding of the concept. And finally, the framework did not analyse the factors influencing the types of continuity of care, which rather seem to merge or be entangled with the definitions, or studied the consequences or outcomes of continuity of care.

2.1.6. Adapting Reid et al.'s framework for the present thesis

In the present thesis, we employ an adapted version of the model elaborated by Reid et al. [9]. The principal introduced change in the original model refers to the inclusion of *accessibility across care levels* (from primary to secondary care and vice versa) as an additional dimension of continuity of clinical management, added to consistency of care and flexibility. In the original model, access was used in a different context considered to be a feature of continuity of relation in the literature on mental health (expressed as *continuity of contact*), that embodied the notion that regular contact is needed to ensure that clinical management goals are adapted and met [37]. Letelier et al. [61] suggested the inclusion of accessibility across care levels – referring to the timeliness of secondary care visits after a primary care referral and vice versa – after conducting an exhaustive literature review for the design and validation of a questionnaire that measures continuity of care, and it was then added to our framework (Table 1).

Table 1: The employed conceptual framework for the analysis of continuity of care across levels of care

Continuity of care		
<i>One patient experiencing care over time as coherent and linked</i>		
Across care levels		Intra-level
Continuity of clinical management	Continuity of information	Continuity of relation
<ul style="list-style-type: none"> • Consistency of care and flexibility 	<ul style="list-style-type: none"> • Information transfer and use 	<ul style="list-style-type: none"> • Ongoing patient-physician relationship
<ul style="list-style-type: none"> • Accessibility across levels of care 	<ul style="list-style-type: none"> • Accumulated knowledge 	<ul style="list-style-type: none"> • Consistency of personnel

Source: Author's own elaboration based on Reid et al. 2002 [9] and Letelier et al. 2010 [61]

2.2. Different approaches for analysing continuity of care

Continuity of care based on the patient's perspective can be analysed by employing qualitative methods (in-depth interviews, focus groups), quantitative methods (surveys to patients or health care users) [18] or by using a mixture of both methods (mixed-methods study).

2.2.1. Analysis of continuity employing qualitative methods

Qualitative methods were particularly employed in studies that aimed at describing the patient's perceptions and experiences of continuity of care [50;60;62-66]. The majority

of these studies were conducted in the English NHS [50;63-65] and focus on one specific chronic condition, such as diabetes [50;60;63] or cancer [65;66]. A few conducted qualitative literature reviews aimed to conceptualize continuity of care, to identify boundaries with related concepts in the nursing research [67] and to refine the development of quantitative data collection instruments [54]. A literature review on cancer care including both quantitative and qualitative methods targeted to understand the relevance attributed to the three types of continuity of care [68]. Only a few qualitative studies [60;62] and syntheses of the literature [48;67] aimed to identify enabling and hampering factors that influence continuity of care. With reference to consequences or outcomes for quality of care, no qualitative study was found that targeted this analysis. The project on continuity of care funded by the English NIHR SDO programme concluded that there is very little qualitative information available that could be interpreted as being about outcomes, and is focusing on continuity of relation only [48;51].

2.2.1. Analysis of continuity employing quantitative methods

Existent quantitative tools mostly focus on one type of continuity, relational continuity [9], one care level, on primary care [69], and one type of pathology [70]. Quantitative instruments for the analysis of relational continuity usually target the analysis of the patients' perceptions of the consistency of personnel, whereby patients are asked whether they have a personal or regular doctor, and the relationship they established with the different providers [9;71]. The duration of the relationship with the professional or the concentration of visits with various providers (for example, via employing the Continuity of Care Index [72]) are also evaluated as part of relational continuity [9;46]. Quantitative instruments for the analysis of continuity of clinical management and information across levels have been developed to a lesser degree [73]. Continuity of information is usually measured by asking patients whether their previous medical examinations and records were available when they had to see their healthcare provider, whether the professional was aware of their previous consultations, whether the medical record was complete and used, and finally whether the problems identified in preceding visits were followed up [9;71]. Three quantitative instruments were developed that embrace the analysis of the three types of continuity of care and their dimensions, and were applicable across care levels: first, the Continuity of Care between Care Levels Questionnaire (CCAENA) validated in Catalonia [73], Colombia and Brazil [74]; second, the Nijmegen Continuity Questionnaire validated in the Netherlands [75], and a third questionnaire validated in Canada [76].

Studies employing quantitative methods analysed the levels of perceived continuity of clinical management and information across care levels [55;77-81] and relational continuity at one care level [77;78] in the organization the patient was attended to, as well as the factors influencing that perception, mainly, however, referring to individual factors of the patient [55;77;78]. Two systematic literature reviews studied the association between the three continuity types and outcomes (mainly health utilization

including hospitalization and emergency visits, and patient satisfaction [47;82], but also health status [47]). One literature review including quantitative studies targeted the analysis of the emphasis and importance cancer patients place on the three types of continuity of care [68].

2.3. State of the art: results on continuity of care

2.3.1. Perceptions of continuity of care

The patient's perception of the existence and experience of continuity of care has been sought by employing qualitative methods in a variety of contexts. According to a meta-summary [54], most studies were conducted in national health systems, particularly the United Kingdom and Canada, and focus on chronic conditions, especially diabetes, and cancer and mentally ill persons. A number of studies described difficulties in delivering all three continuity of care types, which might be explained by the notion that patients especially notice poor continuity [54;56-58], or that studies aimed at identifying breakdowns in order to improve health services, e.g. regarding cancer care coordination [66]. Identified elements of discontinuity refer to, for example, missing referrals between different centres as perceived by cancer patients in Australia [66] or, in the UK, long waiting times and delays in getting appointments for patients with diabetes [50], communication breakdowns as identified by patients with chronic conditions [64] and repeated changes of staff as mentioned by mentally ill patients [83].

Quantitative methods were employed to measure the levels of continuity of care, for example, as perceived by patients attended to in both primary and secondary care [55] and the population receiving paediatric care [81] in the United States, or by patients with multiple chronic conditions aged 60 years and older in the United Kingdom [78]. Again, some studies identified continuity deficiencies of all three types; for instance, less than half of the respondents (44%) of the survey conducted in the US reported that physicians of different care levels worked together to manage a patient's condition [55]. Approximately the same percentage of respondents (46%) highlighted that their primary care physician always seemed informed about care received from specialists [55]. 36% of respondents of a survey conducted in two London boroughs with patients suffering from multiple chronic conditions reported experiencing their medical records not being available to physicians and 29% that different physicians gave them conflicting information about their treatment [78]. With reference to relational continuity, quantitative studies suggest that most patients reported that they had a regular primary care physician [55;84], however with percentages depending on the country [84] from 80% of surveyed patients in the US and 89% in the UK and New Zealand to 100% in the Netherlands [84]. Only very few studies analysed relational continuity with the secondary care physician [85;86].

In Catalonia (Spain), the study context of the present thesis, continuity of care has been analysed in one quantitative study by means of a survey to healthcare users [77;87], which was conducted by the research team in a first step of the analysis of this

phenomenon. Results suggest that transitions between primary and secondary care were mostly reported as connected and consistent; however some noteworthy elements of discontinuity were identified, such as gaps in the transfer of information across levels, long waiting times for secondary care after a referral and low referral rates back to primary care [87]. The need for an in-depth analysis to explore the rationales that could explain these result and thus to understand the full complexity of the phenomenon has been postulated [87].

2.3.2. Perception of factors influencing continuity of care

In qualitative research, only a few original studies [60;62] and two syntheses [48;67] have been conducted that aimed at identifying factors which could influence, i.e. facilitate or distract from, the three types of continuity of care, whilst in other studies influencing factors emerged as a by-product of the study results and occasionally seemed to be entangled with the elements that continuity embraces, thus could difficulty be distinguished from the concept itself. Limited identified factors in qualitative studies relate to the health system (e.g. the clear distribution of roles and responsibilities among different professionals [66;68;88]) and the health care organizations (e.g. co-location of professionals [60;62] and the shortage of health professionals or lack of time [60;89]).

In quantitative research, a number of international studies analysed the individual factors that are associated with the perception of continuity of clinical management and information, such as sex [80], age [55;80], educational level [80] and chronic conditions [78;79]. A tendency can be observed that the elderly population [55;80] and male patients perceive higher levels of continuity of clinical management [55;80], whilst higher education was significantly associated with lower ratings, possibly due to higher expectations [80]. Furthermore, patients with (multiple) chronic conditions reported less favourable experiences with continuity of clinical management and information compared to those with low morbidity scores or no chronic condition, respectively [78;79]. Regarding relational continuity, patients with no chronic conditions and poor self-rated health tended to report increased difficulties of relational continuity [78] as well as younger [77;90;91] and foreign-born patients [90;92;93].

The association between factors related to the health care system, the organizations and the physicians and the three types of continuity has been studied to a lesser degree. With reference to continuity of clinical management and information, the identification of associated factors related to the organization [87;94] and professionals [94] was targeted in two quantitative studies, one conducted in Catalonia [87] and one in Quebec [94]. Results suggest higher perceptions of the two types in the organizations with implemented formal operational agreement with other healthcare establishments (mostly shared-care protocols and mechanisms to facilitate referrals and information sharing) [94] and in the organizations where both primary and secondary care was provided by a single entity [87]. With regard to relational continuity, organizational factors were subject to analysis in a few quantitative studies from the UK

[95;95;96] and Canada [94], which suggested that offering scheduled visits in evenings [94], easier access to the chosen primary care physician [95] and personal list practices (in which patients were encouraged to consult their own doctor) [96] improved perceptions of relational continuity [94]; whilst walk-in care and a high-volume practice style [94] were associated with lower perceptions. The manner these factors influence continuity of care remains unclear, as well as if other important factors exist that might not have been considered so far in the literature.

2.3.3. Consequences of continuity of care for quality of care

Qualitative studies whose objective is to analyse (dis)continuity consequences are non-existent, and little evidence of the possible consequences was provided by the results of the project on the three types of continuity of care funded by the English NIHR SDO programme [48;51]. As a consequence of discontinuity of information, literature predominantly mention the transfer of responsibilities to the patients by, for example, the patients having to act as a mechanism of coordination to maintain the continuity of clinical information [62] or to repeat information (“patients as the information broker”) [60;97]. Qualitative studies that aimed to identify perceived consequences of relational continuity are scarce [98]. Identified consequences of inconsistency of personnel related, for example, to the need to retell antecedents [98], feelings of dissatisfaction [99], helplessness and isolation [83] or confusion by receiving different treatment and medical advice [63]. In turn, an established comfortable relationship was linked with medical concerns being addressed faster, as well as compliance to treatment [98].

Two literature reviews [47;82] summarized the evidence available on the association between the three continuity types and outcomes (mainly health utilization including hospitalization and emergency visits and patient satisfaction [47;82], but also health status [47]). Results generally support an existing association of relational continuity (mainly referring to consistency of personnel) with decreased health care utilization (including hospitalization and emergency visits) and patient satisfaction [82;100;101] and limited associations with clinical outcomes [82;100]. The association of continuity of clinical management and information with health utilization and patient satisfaction is uncertain [82]. Thus, evidence on the links between continuity of care and the different domains of quality of care (safety, effectiveness, patient-centeredness, timeliness, efficiency and equity [102]) remains limited, although continuity of care is already purported to be a critical feature of high quality services [47]. Its analysis might be hampered by the lack of consensus on the subject of whether continuity of care is a process or an outcome measure and how it can be distinguished from other related constructs such as quality of care or patient satisfaction [51], with some authors regarding continuity of care as a process measure [45;103]. Thus a better clarification of the concept is needed for a subsequent analysis to prove the relationship between continuity and its potential outcomes.

2.3.4. Continuity of care in integrated health care networks

Despite the high expectations that have been attached to integrated healthcare networks [104] empirical evidence on the effectiveness and outcomes is scant [18;19;104]. Limited research on the performance of health care networks has been conducted primarily in North America and Europe [18;24] and recently also in Latin America (Brazil and Colombia) [21;105]; however predominantly focusing on the providers' perspective. Regarding continuity of care, it has been questioned if these networks can actually ensure to deliver it [106;107]. Very limited available studies are quantitative, based on cross-sectional surveys, conducted in Canada [52] and the United States [108], with contradictory results: showing, on the one hand, that the patient experience of continuity is positively associated with the existence of formal and informal inter-organizational arrangements between various providers [52]; and on the other hand, limited associations [108].

In Spain, research on the performance of integrated health care networks was conducted in two autonomous communities; Catalonia and the Basque Country [109]. In Catalonia, these networks were the subject of different studies, looking at the organizational elements that might facilitate integrated care [30] and analysing care coordination from the perspective of health professionals and managers [110;111]. Results suggest that factors central to achieving coordination were communication, knowledge and good relationships among professionals. These factors were influenced by professionals' values and the existence of appropriate institutional coordination mechanisms [110]. With reference to the performance of integrated health care networks in continuity of care, studies conducted in Spain are non-existent, except for a survey to users that included two integrated health care network as the study areas [77;87]. Results of the survey suggest that patients attended to in organisations in which primary and secondary care services were managed by the same entity experienced better continuity of care, and that the most favourable reports were given by patients who were attended to at the services managed by a single entity under public law [29].

3. Study context

3.1. The Spanish National Health System

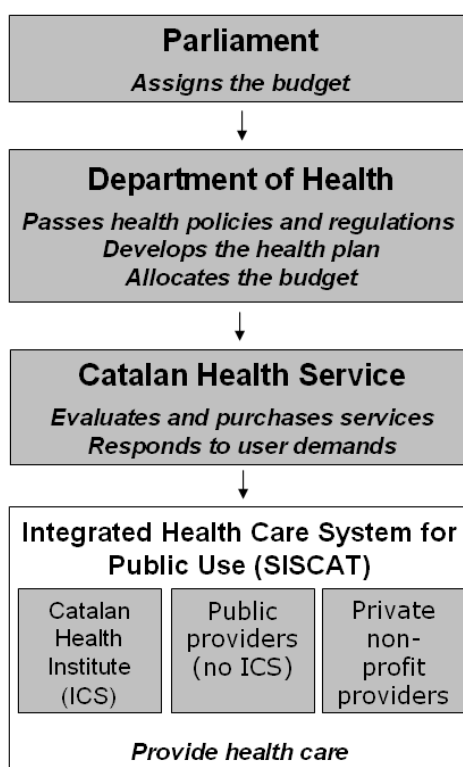
The Spanish health care system was set up as a national health system (NHS; Beveridge model) by the 1986 Health Care General Act (*Ley General de Sanidad*) [112], with general taxation as the main financing source, universal coverage and free access at point of delivery (with the exception of pharmaceuticals prescribed to people aged under 65 not suffering certain chronic diseases, which entail co-payment of 40% of the retail price) [113]. In the 1980s, the NHS was progressively decentralized into its 17 autonomous communities in the context of the political devolution, being Catalonia the first region that received competences on health care in 1981 [113]. In the context of the recent financial crisis, the Royal Decree-Law (*Real decreto-ley*)

16/2012 of the 20 April [114] and 1192/2012 of 3 August [115] introduced changes in the NHS, which included measures related to the entitlement to health care: moving from the right based on citizenship to that of insured beneficiaries.

3.2. The Catalan National Health System

The Catalan health care system is characterized by a split of the financing and provision functions (Figure 3). The Department of Health (*Departament de Salut*), the health authority, is in charge of planning and monitoring health services and allocating the budget. The Department of Health is further responsible for the territorial organization of health services within its jurisdiction: the design of the healthcare areas and basic health zones, and the degree of decentralization to the managerial structures in charge of each [113]. Basic health zones are the smallest units of the organizational structure of health care and are usually organized around a single primary care team [113]. The Catalan Health Service (*Servei Català de la Salut*), a public entity, is responsible for the purchase of primary and secondary services from a number of contracted providers; mainly from the Catalan Health Institute (*Institut Català de la Salut*; ICS), a public company, but also consortia, municipal foundations and private foundations (largely non-profit but also for profit) [116], which make up the Integrated Healthcare System for Public Use (*Sistema sanitari integral d'utilització pública de Catalunya*; SISCAT) [117].

Figure 3. Regulation and governance of the Catalan national health system



Source: Own elaboration based on Decret 196/2010 [117] and Llei 15/1990 [116]

This diversity of providers has originated various management models for the joint management of primary, secondary and long-term care, as for example, integrated health care networks [30;118]. In 2012, twenty integrated health care networks that manage at least primary and secondary care with different degrees of integration were identified in the Catalan public health system [109].

3.3. The organization of health care delivery

In all healthcare areas, both primary health care and secondary (specialized) health care are provided (served by at least one general hospital) [113;119] (Table 2):

- *Primary care* exercises the gatekeeper function and is responsible for coordinating the patient's care along the care continuum. It is composed of primary health care centres and multidisciplinary primary care teams (comprising general practitioners, paediatricians, nurses and in some cases, social workers, midwives and physiotherapists) and provides an integral package of care, covering health promotion, prevention, curative care and rehabilitation [113;119].
- *Secondary or specialist care* acts as a consultant for primary care and is responsible for more complex care. The minimum set of specialized services for general hospitals include teams providing internal medicine, general surgery, core surgical specialties (ophthalmology, ear, nose and throat), orthopaedics, obstetrics and gynaecology, paediatrics, physiotherapy, radiology and laboratories [112;113]. Secondary care can be provided by means of outpatient or inpatient care, or day hospitals, ranging from ambulatory specialized care in different settings (namely, community polyclinics and hospital outpatient clinics) to hospital-based emergency care, medical and surgical day hospitals and hospitalization on an inpatient basis [113;119].

Two emergency entries are available for patients to freely walk in: primary health care centres (for non-life-threatening conditions) and hospital emergency wards (for more urgent hospital care) [113].

Table 2. Organization of the national health system according to the care levels

	Primary care	Secondary care
Features	Geographic accessibility	Technical complexity
Activities	Gatekeeper function; oriented towards health promotion and disease prevention	More complex and costly diagnostic and treatment
Access	Spontaneous or programmed	By referral from primary care professionals for first contact; and spontaneous or programmed
Place of health care provision	Health care centres, local clinics and at patient's home	Outpatient, inpatient or day hospitals

Source: Adapted from Ministry of Health, Social Services and Equality, 2012 [119]

II. JUSTIFICATION

Continuity of care is purported to be a critical feature in delivering high quality healthcare services [47] garnering more attention in the last few years due to the tendency of fragmenting care delivery as a result of specialization health care [8], rapid advances in technology [9], as well as a diversification of providers [8]. Fragmented care or care that is insufficiently coordinated between providers can be harmful to patients due to the duplication of diagnostic tests, inappropriate polypharmacy and conflicting care plans [12]. Problems are most likely to arise at key interfaces, i.e. between primary and secondary care and between specialities [8]; and across the boundaries of one facility or organization [14]. Particularly patients with chronic diseases and pluri-pathologies see an ever-expanding array of different types of healthcare providers in a variety of organizations and settings; thus are exposed to a higher risk of receiving fragmented care. Connecting these components into a smooth care trajectory is increasingly difficult [9;47;120].

Continuity of care is 'how one patient experiences care over time as coherent and linked' [9]; thus is the patient's perception of the coordination of services [9;37], embracing three types: continuity of clinical management, continuity of information and relational continuity. Analysing continuity of care by seeking the patient's perception endows one main benefit: patients can provide a global picture of their care received since they experience services along the continuum of care [54] and first-hand from multiple providers [55]. By being aware of the patient's perception of continuity of care, its consequences and factors influencing it, we are able to adapt the provision of healthcare services to their actual healthcare needs.

The analysis of continuity across care levels conducted to the present moment is still limited. Most qualitative and quantitative studies focus on the analysis of one type of continuity, relational continuity, thus on one care level [9] particularly the primary care setting [69]; whereas studies on continuity of clinical management and information across the care levels are scant. Furthermore, published studies concentrate on analysing the perception of patients with one specific type of pathology [70], such as diabetes [50;60;63] or cancer [65;66]. Less is known about the perception of continuity of care from the point of view of patients with various types of pathologies or acute symptoms who might show differing needs. Only a very studies have been conducted that aimed to identify enabling and hampering factors that influence continuity of care [48;60;67]; in quantitative research these studies mainly refer to individual factors of the patient [55;77;78]. Similarly, regarding the analysis of continuity consequences, in both qualitative [48;51] and quantitative research [47;82] little information has been published so far with uncertain results regarding the association between continuity of clinical management and information and health utilization and patient satisfaction [82]. This lack of studies might be partly due to the multidimensional nature of continuity of care and to certain limitations of the defined conceptual framework.

In Catalonia, the three types of continuity of care have only been analysed in a quantitative study by means of a survey of healthcare users [77;87] that aimed at analysing the degree of perceived continuity of care and its influencing factors related to the patient and the organization. The need for an in-depth analysis to obtain a better understanding of the results for obtaining has been postulated [87].

The performance of integrated health care networks has mainly been studied regarding care coordination, i.e. from the provider's perspective, although also to a limited degree; whereas even less studies on continuity of care are available [52;108]; hence, it has been questioned if these networks can actually ensure to deliver it [106;107].

The present thesis forms part of the research line on *Care Integration* in Catalonia and Latin America of the *Health Policy and Health Services Research Group* of the public *Consortium for Health Care and Social Services of Catalonia* which aims to analyse the integration of health care and its implications for the continuity of care, quality, access and efficiency of the health system. This research line began with the development of a framework for the analysis of integrated health organizations, which integrated the knowledge available on that topic and supported the analysis of the succeeding projects. Initially, six integrated health care organizations in Catalonia and their results on coordination and continuity of care were analysed (funding received by ISCIII and FEDER PI04/2688). Continuity of care was analysed in a multiple case study of COPD patients in four selected integrated health organizations, which results form part of this thesis. Later on, the study of continuity of care was extended to other healthcare areas of the Catalan health care system (selection of areas with different management models of the two care levels), first by applying a questionnaire (PI08/90154) and second by conducting semi-structured interviews with users of health services (PI10/00348). The results obtained in the latter study also form part of this thesis. Finally, the research on care integration was extended to different health systems in Latin America within the framework of two European projects, by first adapting the conceptual frameworks and tools and second analysing the coordination and continuity of care in different health care network of Latin-American countries (funded by the European Commission: Equity-LA FP7-Health-2007-B, and Equity-LA II FP7-Health-2012-B).

III. RESEARCH QUESTIONS AND STUDY OBJECTIVES

Research questions

The present thesis aims to contribute to the advancing of the knowledge about the healthcare user's perspective of continuity across care levels by responding to the following research questions:

What is the health care user's perception of the existence of continuity across care levels in the healthcare areas they are attended to?

What are the perceived factors influencing continuity across care levels?

What are the perceived consequences of continuity across care levels?

Study objectives

In response to the study questions, the following general and specific objectives were developed:

General objective

To analyse the healthcare user's perception of continuity across care levels in different healthcare areas in the Catalan healthcare system, as well as its influencing factors and consequences.

Specific objectives

- To analyse the existent knowledge of patients' perceptions of continuity of care, its influencing factors and consequences
- To explore the COPD patient's perception of the existence of continuity of care in different Catalan integrated health care networks
- To analyse the health care user's perception of the existence of continuity of care in different areas in the Catalan national health system
- To identify the factors influencing continuity of care from the point of view of the health care user of the Catalan national health system
- To identify the consequences of continuity of care from the perception of the health care user of the Catalan national health system

IV. METHODS

The research consisted of three individual studies addressing different aspects of continuity of care. Each study applied a different qualitative method, which is summarized at the end of this chapter (Table 5).

Study 1: What is known about continuity of care?

Study objective

To contribute to improving the knowledge on patients' perceptions of continuity of clinical management and information across care levels and relational continuity based on the review of qualitative studies.

Study design

A descriptive meta-synthesis of published qualitative research that examined patients' perceptions and experiences on continuity of care was conducted. A meta-synthesis is the analysis of qualitative findings that are themselves interpretative syntheses of data [121].

Search strategy and selection process

A literature search in various electronic databases (Medline, Social Sciences Citation Index and Science Citation Index Expanded) was undertaken to minimize the likelihood of excluding relevant studies. The search strategy included the combination of descriptors and keywords relating to the research area (i.e., 'continuity of care' or linked key terms that were similar in meaning), qualitative studies and the patient's perspective. Furthermore, reference lists of selected articles were hand searched and the Internet search tool of the Reference Manager Version 11 used to identify additional articles that met the following inclusion criteria: (i) relevance to the research topic, (ii) original studies that adopted a qualitative design, (iii) investigating the patient's perspective, and (iv) published in English, German or Spanish. 23 studies met the inclusion criteria and were retrieved for further analysis. No additional article was identified through hand searching of the reference lists; however, two studies were included by using the Internet search tool of the Reference Manager.

Data analysis

A content analysis was conducted largely following the classic method by Noblit and Hare [122]. The analysis began with creating a grid of key themes emerging from the articles and was followed by the identification of homogeneity and discordance of themes. The identification of new themes or categories was the next step used in the content analysis. Findings were classified by each type and dimension of continuity, according to the theoretical framework created by Reid et al. [9]

Quality control

Selected articles were checked if their applied methodology in the recruitment process, data collection and analysis fulfilled quality standards according to May and Pope's criteria of validity [123]. Discussions of experienced researchers took place in cases of uncertainty if the study (i) responded to our research purpose and (ii) applied adequate techniques and tools to strengthen rigour.

Study 2: COPD patients' perceptions of continuity of care in integrated health care networks

Study objective

To contribute to the analysis of integrated health care networks' performance by analysing the COPD patients' perceptions of continuity of clinical management and information across care levels and continuity of relation in integrated health care networks of the public health care system of Catalonia.

Study design

A descriptive-interpretative, qualitative study was conducted using a phenomenological approach and a multiple case study design. Studies that draw upon the phenomenological perspective concentrate on exploring how individuals make sense of the world in terms of the meanings and classifications they employ [124]. The purpose of case studies is to gather comprehensive, systematic and in-depth information about each case of interest [125]. A case of interest has defined boundaries within their contexts and can be an individual, an organization, a region, a country, etc. [126]. By adopting a case study design, the phenomenon of continuity of care can be understood in its multifaceted manner using different sets of information [126] (here, the patients, their providers and electronic medical records). In a multiple case study, analyses on two or more units are conducted [126], enabling the exploration of differences between cases [127].

Sample

A theoretical sample [128] was designed consisting of two stages. In the first stage, the study contexts, i.e. four integrated healthcare networks of the Catalonian public healthcare system were selected applying the following criteria: (i) provision of primary and secondary care (comprising at least one hospital), (ii) joint management for over five years and iii) delivery of healthcare services to a defined population. The selected networks showed similarities regarding the level of internal production of services (100%) but differences related to the integration depth (the number of units providing the same services), inter-organisational relationship (type of agreement) and types of care coordination mechanisms implemented (Table 3). In the second stage, two study cases of each integrated healthcare network were selected; a study case consisted of one COPD patient. COPD was selected as the tracer condition since COPD patients

require care provided by primary and secondary care professionals over time [129;130]. COPD patients were selected according to the following criteria: (i) confirmed COPD diagnosis, (ii) chronicity ≥ 5 years, (iii) having received care for at least 2 years at the network, and (iv) utilisation of at least 2 levels of care in the last six months.

Data collection

Data were retrieved by means of individual semi-structured interviews with COPD patients. Patients identified most relevant health professional in their COPD care which were his/her primary care physician, his/her pulmonologist or case manager (secondary care nurse). Furthermore, data were obtained by the review of the COPD patients' medical records. Specific topic guides were elaborated for patients (Annexe 2.1.) and health professionals (Annexe 2.2.) comprising two parts: one to reconstruct the clinical trajectory and one to explore their perceptions of the three types of continuity of care (clinical management, information and relation) following Reid et al.'s [9] conceptual framework. Various interviews with the same patients were necessary to accomplish saturation of data. Interviews were audio-recorded and transcribed verbatim. The patients' medical records were reviewed using a structured guide (Annexe 2.3.) to contrast the data obtained from the interviews.

Data analysis

A thematic content analysis was conducted with support of the software Atlas-ti 5.0. Data were segmented by case and information source. The discovery and pre-analysis phase consisted of the iterative reading of the interviews, followed by a mixed generation of categories [131]: we combined deductive and inductive analysis, two complementary strategies [132], i.e. we based our analysis on the conceptual framework reflected in the topic guides (deduction) but left room for new elements to emerge (induction). A study narrative was written for each case, which represented a comprehensive, descriptive data presentation (case-oriented analysis including the COPD patient, his health professionals and medical records). In a second step, a category-oriented analysis across integrated healthcare networks was conducted to identify key categories [133].

Quality control

Quality was guaranteed by applying an adequate design of the study, recruiting those COPD patients who possessed the most relevant characteristics for studying the phenomenon of continuity of care. Triangulation of information from different sources (patients, their physicians and clinical records) ensured comprehensiveness of data collection, encouraged a more reflexive data analysis and reinforced the trustworthiness of results [123]. The participation of six researchers, who were knowledgeable about qualitative investigation and the phenomenon of continuity of care, in the analysis of the data enhanced accuracy of findings.

Ethical approach

The study was conducted in accordance with the European and Spanish legislation on ethical research (Ley Orgánica 15/1999; Real Decreto 1720/2007). Ethical considerations were taken into account during the interview and data analysis: any questions about the study by the participants were discussed in full and consent form was signed before the interview. Selected users were advised that participation was entirely voluntary, that withdrawal at any point was possible and that their participation would not affect their treatment in any way. Respondent names were changed during analysis, and other strong identifiers altered in the used quotations.

Table 3. Key characteristics of selected integrated healthcare networks

	BSA	CSdM	CSdT/FHSLL	SSIBE
Integration width	Primary, secondary and long-term care	Primary, secondary and long-term care	Primary, secondary and long-term care	Primary, secondary and long-term care
Integration depth	6 Primary care centres 1 Local clinic 1 General hospital 1 Long-term care centre 1 Centre for sexual and reproductive health	3 Primary care centres 5 Local clinics 1 Tertiary hospital 1 Mental health care centre 1 Long-term care centre 1 Retirement home	4 Primary care centres 2 Local clinics 1 Tertiary hospital 1 Mental health care centre 1 Long-term care centre	4 Primary care centres 28 Local clinics 1 General hospital 1 Long-term care centre 2 Nursing homes
Level of internal production of services	100%	100%	100%	100%
Inter-organizational relationship	None	Consortium	Contract	Association of economic interests
Information system	Shared different electronic medical records	Different electronic medical records, sharing of some information	Different electronic medical records, sharing of some information	Shared single electronic medical records
Specific care coordination strategies for COPD	Shared clinical guidelines Cross-level shared electronic COPD patient register	Part of COPD care management integrated in primary care through, e.g., decentralization of diagnostic tests	Shared clinical guidelines Cross-level shared electronic COPD patient register Direct access to secondary care for COPD patients stage II-IV	Shared clinical guidelines Cross-level shared electronic COPD patient register COPD care management integrated in primary care with the general practitioner acting as the disease manager and the pulmonologist as the consultant

BSA: Badalona Serveis Assistencials; COPD: chronic obstructive pulmonary disease; CSdM: Consorci Sanitari del Maresme; CSdT/FHSLL: Consorci Sanitari de Terrassa-Fundació Hospital Sant Llàtzer; SSIBE: Serveis de Salut Integrats del Baix Empordà

Source: Vázquez et al. [30;109]

Study 3: Continuity of care perceptions of users of different healthcare areas in Catalonia

Study objectives

To analyse the perceptions of continuity of clinical management and information across care levels and relational continuity at the intra-level, as well as the factors influencing it, from the viewpoint of users of the Catalan national health system.

Study design

A descriptive-interpretative qualitative study on continuity of care was conducted using a phenomenological approach. To orient the study of the phenomenon - continuity of care - the conceptual framework created by Reid et al. [4] was employed.

Sample

A two-stage theoretical sample was designed. In the first stage, the study contexts were selected to represent the diversity of management models for the health services. The contexts chosen were three healthcare areas in the NHS of Catalonia: the Baix Empordà region, the city of Girona and Ciutat Vella in Barcelona (Table 4). All three areas have implemented similar mechanisms for clinical coordination across levels, such as shared clinical guidelines and protocols, virtual curbside consultations of primary care doctors with specialists, periodic discussion of clinical cases and automatic notification of hospital discharge for primary care follow-up. The information system implemented, however, differs according to the area (i.e. one/two shared/not shared electronic medical record system(s)).

In the second stage, in each context, the informants were selected according to the following criteria: healthcare user of 18 years of age or over who had been attended to in both primary and secondary care for the same health problem within the three months prior to the interview. Variation criteria were considered during the selection process (taking into account sex, age, country of origin and the use of different services depending on the health issues) in order to take in a broad set of data and experiences (maximum-variation sampling [128]). The final sample consisted of 49 users, between 14 and 18 per area.

Table 4. Description of the study areas

	Baix Empordà Region	City of Girona	Ciutat Vella of Barcelona
Population*	74,144	83,312	99,093
Location	Rural and semi-urban	Urban	Urban
Primary care providers			
<i>Number of basic health zones</i>	4	4	5
<i>Managing entity/entities</i>	SSIBE	ICS	ICS (4 zones) PAMEM (1 zone)
Secondary care providers			
<i>Number of hospitals</i>	1	1	1
<i>Managing entity</i>	SSIBE	ICS	PSMAR
Information system	Single shared electronic medical record system	Two shared electronic medical record system	Two electronic medical record systems; not shared (ICS with PSMAR) and shared (PAMEM with PSMAR)

* Population \geq 18 years of age; Source: Registro Central de Asegurados 2010 [134]

ICS: Institut Català de la Salut; **PAMEM:** Institut de Prestacions d'Assistència Mèdica al Personal Municipal; **PSMAR:** Parc de Salut Mar; **SSIBE:** Serveis de Salut Integrats Baix Empordà;

Data collection

The data were collected through individual semi-structured interviews. An interview topic guide on continuity of care was drawn up containing two main parts (Annexe 2.4.): a general part about the user's health status (serving as an icebreaker) and their experiences with the healthcare services, and a specific part about their perceptions of continuity of care during these experiences. The latter part was oriented by Reid et al.'s conceptual framework [9]. All interviews were audio taped, transcribed in full, anonymized, and checked against the tape by the first author. Data collection stopped when saturation was reached in each area, which was when encounters with new participants no longer elicited themes which had not been raised by previous participants [128]. Field notes on preliminary ideas and reflections were made continuously to enhance reflexivity, thus acknowledging the influence a researcher has on the research process [128].

Data analysis

A thematic content analysis was conducted by the first author using the software Atlas-ti 5.0. Data were segmented by study area and themes. Following initial familiarization with the interview contents, a mixed generation of categories i.e. we based our analysis on the categories used in the topic guides but left room for new categories to emerge [132]. Transcripts were coded and categories were developed and refined as new sections of text were examined. The final list of categories consisted of the perception

of the existence of each continuity of care dimension across levels and its defining elements, influencing factors and consequences.

Quality control

Four experienced researchers participated in the data analysis which guaranteed the accuracy of findings.

Ethical approval

The study protocol was approved by the ethics committee of Parc de Salut Mar (2010/412/1). As in the second study, ethical considerations included written informed consent sought from each participant and masking of data to ensure anonymity and confidentiality.

Table 5. Overview of study methods of the three studies

	Study 1	Study 2	Study 3
Study design	Descriptive meta-synthesis	Interpretative, qualitative multiple-case study	Descriptive-interpretative qualitative study
Sample	25 original studies published from 1999 to 2009 that adopted a qualitative design and investigating the patient's perspective on continuity of care	Theoretical sample in two stages: (i) Four integrated healthcare networks of the Catalanian public healthcare system (ii) Two study cases of each network; each case consists of one COPD patient, his/her primary care physician, his/her pulmonologist or case manager and his/her medical records	Theoretical sample in two stages: (i) The study contexts: healthcare areas in Catalonia with different management models of services (ii) users ≥ 18 years who were attended to at both care levels for the same health problem in the last 3 months prior to the interview
Data collection	Literature search in different electronic databases (Medline, Social Sciences Citation Index and Science Citation Index Expanded) Hand-searching of reference lists Internet search tool of Reference Manager	Individual semi-structured interviews with patients and their health professionals Review of COPD patients' medical records	Individual semi-structured interviews with health care users
Data analysis	Thematic content analysis Identification of homogeneity and discordance of themes	Thematic content analysis Data segmentation by area and case Mixed generation of categories	Thematic content analysis Data segmentation by area and themes Mixed generation of categories
Quality control	Selection of articles that followed a rigorous methodology Triangulation of researchers in cases of uncertainty	Triangulation of information from different sources Participation of experienced researchers in data analysis	Participation of experienced researchers in data analysis
Ethical approach	Not applicable	Study conducted in accordance with the European and Spanish legislation on ethical research (<i>Ley Orgánica 15/1999; Real Decreto 1720/2007</i>) Approval of the study protocol by the ethics representative of the CSC	Applied legislation as described in the previous study Approval of the study protocol by the Ethics Committee of Clinical Research <i>Parc Salut Mar (2010/4124/I)</i>

V. RESULTS

Four articles constitute the results of the present thesis:

Article 1: Waibel S, Henao D, Vargas I, Aller MB, Vázquez ML. Patients' perceptions of continuity of care: meta-synthesis of qualitative studies. *International Journal for Quality in Health Care*. 2012; 24(1):39-48

Article 2: Waibel S, Vargas I, Aller MB, Gusmão R, Henao D, Vázquez ML. The performance of integrated health care networks in continuity of care: a qualitative multiple case study of COPD patients. *International Journal of Integrated Care*. 2015; Jul 20;15:e029

Article 3: Waibel S, Vargas I, Aller MB, Coderch J, Farré J, Vázquez ML. Continuity of clinical management and information across care levels: perceptions of users of different healthcare areas in the Catalan national health system. *Submitted to BMC Health Services Research*.

Article 4: Waibel S, Vargas I, Aller MB, Vázquez ML. Relational continuity with primary and secondary care physicians in the Catalan national health system. *In elaboration*.

Article 1

What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies

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Accepted for publication 29 October 2011

Abstract

Objective. The increasing complexity in healthcare delivery might impede the achievement of continuity of care, being defined as 'one patient experiencing care over time as coherent and linked'. This article aims to improve the knowledge on patients' perceptions of relational (RC), informational (IC) and management continuity (MC) across care levels.

Design. A descriptive, qualitative meta-synthesis was conducted based on a literature search in various electronic databases using the subject heading 'continuity of care' and linked key terms. We scanned retrieved articles for adherence to inclusion criteria: (i) relevance to research topic, (ii) original study adopting a qualitative design and (iii) investigating the patient's perspective. Content analysis was conducted by identification of themes and aggregation of findings.

Results. The selected 25 studies most frequently investigated RC. Being attended to regularly and over time by one physician (RC) was valued by chronic ill patients, but balanced with convenient access by young patients (MC). Communication and information transfer across care settings as well as the gathering of holistic information about the patient were perceived to foster IC. Critical features for achieving MC were accessibility between care levels, individualized care and a smooth discharge process including the receipt of support. Patients further considered that their personal involvement was one facilitating element of continuity of care.

Conclusions. Patients identified elements that enhance or distract from continuity of care across boundaries. Variations in perceived importance seem to depend on both individual and contextual factors which should be taken into account during healthcare provision.

Keywords: continuity of patient care, qualitative research, meta-synthesis, patient-centred care, physician–patient relations, information management

Introduction

Rapid advances, new treatments, high specialization and shifts in care from institutional to outpatient and home settings mean that patients see an ever-expanding array of different types of providers in a variety of places [1, 2]. That is particularly the case in patients with chronic diseases or pluripathologies who receive care from multiple disciplines [3–5]. Policy-makers and healthcare providers increasingly express concerns about that fragmentation of care [1]. Connecting the care components into a smooth trajectory can be challenging [1]. Continuity of care is purported to be a critical feature in delivering healthcare services [4].

Literature on continuity of care suggests better outcomes when present in healthcare provision, e.g. higher patient satisfaction with medical care [6–9], improved delivery of preventive services [8, 9] and lower hospitalization rates [7–9].

Due to the tendency of segmenting care delivery, the concept of continuity of care has been garnering more attention in the last few years. This has been accompanied by a discussion on clarifying its conceptual boundaries, most lately in Parker *et al.* [10] and Freeman and Hughes [11]. Maybe the widest accepted conceptual framework is that of Reid *et al.*, who define continuity of care as one patient experiencing care over time as coherent and linked [1]; similar to Freeman *et al.*'s description: the experience of a smooth and coordinated progression of care from the


Article 2

Volume 15, 20 July 2015

Publisher: Uopen Journals

URL: <http://www.ijic.org>

Cite this as: Int J Integr Care 2015; Jul-Sep; URN:NBN:NL:UI:10-1-114834

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Submitted: 12 February 2014, revised 29 May 2015, accepted 4 June 2015

Research and Theory

The performance of integrated health care networks in continuity of care: a qualitative multiple case study of COPD patients

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Abstract

Background: Integrated health care networks (IHN) are promoted in numerous countries as a response to fragmented care delivery by providing a coordinated continuum of services to a defined population. However, evidence on their effectiveness and outcome is scarce, particularly considering continuity across levels of care; that is the patient's experience of connected and coherent care received from professionals of the different care levels over time. The objective was to analyse the chronic obstructive pulmonary disease (COPD) patients' perceptions of continuity of clinical management and information across care levels and continuity of relation in IHN of the public health care system of Catalonia.

Methods: A qualitative multiple case study was conducted, where the cases are COPD patients. A theoretical sample was selected in two stages: (1) study contexts: IHN and (2) study cases consisting of COPD patients. Data were collected by means of individual, semi-structured interviews to the patients, their general practitioners and pulmonologists and review of records. A thematic content analysis segmented by IHN and cases with a triangulation of sources and analysts was carried out.

Results: COPD patients of all networks perceived that continuity of clinical management was existent due to clear distribution of roles for COPD care across levels, rapid access to care during exacerbations and referrals to secondary care when needed; nevertheless, patients of some networks highlighted too long waiting times to non-urgent secondary care. Physicians generally agreed with patients, however, also indicated unclear distribution of roles, some inadequate referrals and long waiting times to primary care in some networks. Concerning continuity of information, patients across networks considered that their clinical information was transferred across levels via computer

Article 3

Continuity of clinical management and information across care levels: perceptions of users of different healthcare areas in the Catalan national health system

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ABSTRACT

Background: The integration of health care has become a priority in most health systems, as patients increasingly receive care from several professionals in various different settings and institutions, particularly those with chronic conditions and multi-morbidities. Continuity of care is defined as one patient experiencing care over time as connected and coherent with his or her health needs and personal circumstances. The objective is to analyse perceptions of continuity of clinical management and information across care levels and the factors influencing it, from the viewpoint of users of the Catalan national health system.

Methods: A descriptive-interpretative qualitative study was conducted using a phenomenological approach. A two-stage theoretical sample was selected: (i) the study contexts: healthcare areas in Catalonia with different services management models; (ii) users ≥ 18 years of age who were attended to at both care levels for the same health problem. Data were collected by means of individual semi-structured interviews with patients (49). All interviews were recorded and transcribed. A thematic content analysis was conducted segmented by study area, with a mixed generation of categories and triangulation of analysts.

Results: Patients in all three areas generally perceived that continuity of clinical management across levels existed, on referring to consistent care (same diagnosis and treatment by doctors of both care levels, no incompatibilities of prescribed medications, referrals across levels when needed) and accessibility across levels (timeliness of appointments). In terms of continuity of information, patients in most areas mentioned the existence of information sharing via computer and its adequate usage. Only a few patients reported elements of discontinuity in the care received. Numerous factors influencing continuity were identified by patients, related to the health system itself (clear distribution of roles), its organization (insufficient resources, care coordination mechanisms, co-location) and physicians (willingness to collaborate, commitment to patient care, the primary care physician's technical competence).

Conclusions: Continuity across care levels appears to exist in the areas studied, with certain exceptions that highlight where there is room for improvement. Influencing factors can offer valuable insights on where to direct coordination efforts.

KEYWORDS: Continuity of patient care, qualitative research, quality of health care, health information management, patient care management, patient navigation

Article 4

Relational continuity with primary and secondary care physicians in the Catalan national health system

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ABSTRACT

Introduction: The importance of a patient-physician relationship has been neglected by recent policy in different countries, although it has been argued to be the antidote to increasingly fragmented and depersonalized health care systems. Relational continuity is the patient's perception of an ongoing therapeutic relationship with one or more providers spanning different health care episodes and characterized by two dimensions: consistency of personnel and ongoing patient-provider relationship. The objective is to analyze the perceptions of relational continuity with the primary and secondary care physicians, its influencing factors and consequences from the viewpoint of users of the Catalan national health system.

Methods: An interpretative qualitative study was conducted with a selected two-stage theoretical sample: (i) the study contexts: healthcare areas in Catalonia with different services management models; (ii) users ≥ 18 years of age who were attended to at both care levels for the same health problem. Data were collected by means of individual semi-structured interviews with patients (49). All interviews were recorded and transcribed. A thematic content analysis was conducted segmented by study area, with a mixed generation of categories and triangulation of analysts.

Results: Patients across the three healthcare areas studied generally perceived that consistency of primary care personnel was existent given that they were usually seen by the same physician over longer periods of time, as well as in rare occasions by locum doctors. With reference to secondary care, numerous patients of all the areas indicated inconsistencies. Nearly all patients who perceive consistency of personnel also described an ongoing relationship with their primary and secondary care physician that is characterised by mutual accumulated knowledge and the patient's personal trust in the assigned physician. Relational (dis)continuity was linked to a variety of influencing factors. Organizational factors – some of which were specific to the study area – appeared to affect the consistency of personnel: an adequate appointment making system (arranged visits with the assigned physicians according to their availability) and a small size of the primary care centre (lack of possibilities to change physicians) were considered to favour consistency; whilst the re-organization of patient lists (assignment to new physicians) distracted from it. The development of an ongoing patient-physician relationship was influenced by the stability of personnel and frequency of visits as well as by a combination of factors related to physicians; that were an adequate medical practice or provided technical quality, an effective patient-physician communication and the physician's commitment to patient care.

Conclusions: Perceptions of the existence of relational continuity are similar in the selected healthcare areas; however differ depending on the care level. Organizational factors influence the consistency of personnel; whilst factors related to physicians affect the development of an ongoing relationship together with the stability of personnel. Thus the two dimensions of relational continuity appeared to be interlinked.

KEYWORDS: continuity of patient care, patient-doctor relationship, qualitative research, patient perspective, trust;

VI. DISCUSSION

1. Contribution of the thesis and strengths

This thesis addresses a topic of current relevance in the analysis of health care: the continuity of health care across the care levels. It contributes to filling the existing knowledge gap by providing a better understanding of the phenomenon through the analysis of the information available in the international literature on it three types (continuity of clinical management and information across the care levels and relational continuity with the primary and secondary care physician). Furthermore, for this thesis new data was generated regarding continuity of care as perceived by healthcare users attended to in different healthcare areas in the national health system (NHS) of Catalonia (organizations with different management models of primary and secondary care, and including integrated health care networks). Patients with different types of conditions were selected to gain variation in the discourse. Apart from their perceptions of continuity of care in the organization they were served, information on the different factors that influence (dis)continuity of care was sought, as well as the consequences of (dis)continuity for quality of care. Finally, this thesis contributes to a better understanding of the conceptual framework developed by Reid et al. [9] by developing it further, on the basis of the information retrieved in the meta-synthesis and in the Catalan organizations. Specific recommendation for health care managers and professionals are provided, with the objective to improve the provision of healthcare services regarding continuity of care.

The combination of qualitative research (meta-synthesis, multiple case-study and qualitative study) in three studies that comprise the thesis can be considered to be a major strength. The extensive international literature review conducted initially allowed for in-depth analysis of the conceptual framework of Reid et al. [9], which were employed in this thesis, and for identifying knowledge gaps on continuity of care. The synthesis further provided a firm knowledge base that supported the interpretation of the obtained results in the other studies and fed into their discussion. Including different qualitative approaches in the two studies conducted in Catalonia allowed for corroborating results about the same phenomenon but with slightly different contexts.

The rigor and soundness of the methodology employed can be considered to be additional strengths of the thesis. First, consistency between the study problem and the defined theoretical and methodological approach were achieved, as well as between the study objectives and the employed methods, by means of the inclusion of different study areas that captured an important part of the healthcare situations possible of the Catalan NHS and the selection of informants with profiles relevant to the study phenomenon. Second, various strategies that guaranteed the quality of the research were included, for instance, the triangulation of different sources of information, the participation of several researchers knowledgeable about the topic in the analysis and interpretation of data and the detailed description of the research process.

2. Perception of continuity of care

Patients across the study areas of Catalonia including the integrated health care networks generally perceive that the three types of continuity of care are existent; however also identify some interruptions of all three types and in all study areas.

2.1. Perception of continuity of clinical management across care levels

Patients served in all study areas of the Catalan NHS (including COPD patients attended to in the selected integrated healthcare networks) perceive that they receive the same diagnosis and treatment from physicians of the different care levels and with referrals to the other care level when necessary. Only a small number of patients in all areas identified specific elements of discontinuity, such as inconsistencies in treatment, the unnecessary repetition of tests or missing referrals to secondary care. Discontinuity elements identified in qualitative literature usually related to adequate referrals and accessibility across care levels, as confirmed by the meta-synthesis, for example, missing referrals between different centres as perceived by cancer patients in Australia [66] or long waiting times and delays in getting appointments for patients with diabetes attended to in England [50].

With regard to access across levels, patients consistently perceive timeliness of appointments in urgent matters, which in the case of COPD patients was during exacerbations, given immediate or rapid access to primary or secondary care or urgent referrals. Nevertheless, waiting times for non-urgent secondary care visits were highlighted to be long or too long by numerous patients, which was in concordance with the results of a user survey conducted in Catalonia, where nearly half of the interviewees (42%) held the opinion that waiting times for secondary care after a referral were long or excessive [87]. In a different survey conducted in the whole region of Catalonia, a lower percentage of respondents (20%) reported that accessibility to secondary care was poor or regular; however including also direct access to secondary care [135]. The different results of the surveys might indicate that more difficulties were encountered when accessing secondary care via a primary care referral. Our results further show the importance of available alternative entry points to the system, for example, the possibility of seeking emergency care when the condition worsened and waiting times for the upcoming secondary care appointment were too long. In the literature, the importance of “getting in” for patients (gaining access to appropriate care) has been described, which, when achieved, was accompanied by feelings of intense relief [136] and a sense of security as perceived by COPD patients [58].

2.2. Perception of continuity of information across care levels

Results of the two studies conducted in Catalonia are consistent, suggesting that both COPD patients of the integrated health care networks and users served in the different study areas generally perceive that their clinical information is registered, transferred via computer across levels and up taken by the physicians; results largely in keeping with those of the user survey, where most interviewees (82% and 81%) reported that

the secondary care physician was aware of the reason for their visit and tests carried out at primary care level; and the primary care physician of the instructions received from the secondary care level [87]. Patients indicated that information was shared given that there was no need to repeat antecedents or deliver test results to physicians of the other care level. Haggerty et al. [54] concluded from their meta-summary that information transfer between professionals was assumed by patients until proven otherwise, i.e. when no problems have occurred.

One exception to the fact that information transfer is generally perceived to exist in the Catalan NHS emerged from the discourse of users assigned to Ciutat Vella in Barcelona (in the area where primary and secondary care were managed by different entities) given that information was reported to be only partially shared across the care levels. Likewise, in the survey, patients attended to in Barcelona reported lower levels of information transfer than patients from the other healthcare areas where primary and secondary care was managed by the same entity [87]. Thus, results might suggest that the organizations in Catalonia that managed both primary and secondary care achieved to deliver continuity of information. Limited literature further indicates better performance of high integrated health care networks in Canada versus low integrated networks, with regard to perceived less information gaps and better circulation of information between professionals [52]. Nevertheless, attention should be drawn to the gaps highlighted by a small number of patients, for example specific information not being shared via computer or data stored in the records not always being consulted by locum and emergency doctors. According to the results of the meta-synthesis, deficiencies in information transfer were frequently highlighted in different contexts, for example in England by patients with chronic conditions who were dissatisfied because of insufficient information transfer after hospital discharge [64] or by patients using the emergency and urgent care system who became frustrated because patient records were sometimes unavailable and not shared with the different services [97].

2.3. Perception of relational continuity in primary and secondary care

Results on relational continuity show some differing aspects across the organizations studied and between the care levels. Most patients of the different study areas highlighted that they were usually seen by the same primary care physician over long periods of time, as well as in rare occasions by locum doctors, which they highly valued; whilst, COPD patients of some integrated health care network indicated turnover of primary care physicians. With reference to secondary care, numerous patients of both studies perceived inconsistencies; however most of them did not identify that to be a problem given that all specialists were considered to be competent. In contrast, results of the survey suggested that more healthcare users reported having been seen by the same secondary care physician for the same condition in the last year than by the same primary care physician (85% versus 80%); with some differences observed in the study areas [87]. Numerous international studies, particularly quantitative in nature, analysed the levels of perceived consistency of

primary care doctors [55;84;137]. According to a cross-sectional study conducted in seven countries (Australia, Canada, Germany, the Netherlands, New Zealand, the UK and the US), most patients reported that they had a regular primary care physician, however percentages depended on the country and varied from 80% of surveyed patients in the US and 89% in the UK and New Zealand to 100% in the Netherlands. Responses varied widely regarding whether these primary care sources offer office hours outside of the nine-to-five work week and enable easy contact by phone [84]. The perceived consistency of secondary care personnel was studied to a lesser degree in the literature [85;86]; with one US study concluding that the consistency of specialists varied tremendously by the specialty [85].

Nearly all patients who perceive consistency of personnel also describe an ongoing relationship with their primary and secondary care physician that is characterised by mutual accumulated knowledge and the patient's personal trust in the assigned physician. These interlinkages between the two dimensions of relational continuity have also become clear in the meta-synthesis, as well as in another systematic review of qualitative studies on the patient-doctor relationship [138].

3. Factors favouring or hindering continuity of care

Numerous factors influencing (dis)continuity of care have been identified, related to the healthcare system, the health care organization and physicians.

3.1. Factors related to the healthcare system

From the discourse of patients served in the Catalan healthcare system it became apparent that the clear distribution of roles between primary and secondary care physicians favoured continuity of clinical management across care levels, by means of enhancing consistency in diagnosis and treatment and avoiding incompatibilities of prescribed medication and duplications of tests. According to the results of the meta-synthesis, patient value that *one* clinician took over responsibilities and coordinated their care; to prevent them from falling through the gaps [139]. Patients highlighted that their physicians assumed differing, not overlapping tasks in managing their condition: primary care physicians were in charge of resolving minor health problems, updating the medication plan according to the specialist's instructions, handing over the prescription and in some areas for treating exacerbations. In turn, secondary care physicians were responsible for recommending drugs and modifying the treatment. In the COPD study, specialists were even assigned main responsibility for the COPD care given higher technical competence. In a similar study, COPD patients preferred being in contact with the specialist rather than the primary care physician, who they experienced to be uninterested in or unknowledgeable about their condition [58]. Thus, depending on the intensity of the care needed [140] or the condition the patient is suffering from, their designation of the main responsible professional in their care might change.

With reference to continuity of information and relational continuity, no influencing factors of the health system were identified.

3.2. Factors related to health care organization

A couple of organizational factors were identified to influence continuity of clinical management across the care levels, which were care coordination mechanisms (face-to-face meetings of physicians of the two care levels) and mechanisms for informal communication (use of e-mail and telephone). These mechanisms were in particular mentioned in one study area and were perceived to facilitate diagnosis making and the mutual adaptation of treatment, and resulted in adequate and timely secondary care referrals.

The information transfer across care levels was favoured by implemented care coordination mechanisms (electronic medical records, which was mentioned across all three areas) and the co-location of physicians of both care levels at the primary care centre given that the medical records were accessible to the whole medical staff working in the same facility (specific to two areas). Co-location was mentioned previously in qualitative studies conducted in Canada [60;62]; however in the context of facilitating continuity of clinical management by promoting interactions of healthcare providers and increasing accessibility [60;62]. Patients further highlighted that insufficient resources available, demonstrated by a shortage of doctors and translating into work overload, led to an insufficient uptake of information from the clinical histories, in particular by locum doctors. According to a few patients, high work load was partly due to the reduction of the healthcare budget in Spain in 2012 as a result of the economic crisis [141]. The shortage of provider also emerged to be an influencing factor in other qualitative studies on continuity of care [67]; where this factor – apart from affecting continuity of information (as in a Belgium study, where lack of time distracted from being able to call the specialist to obtain more clinical information [89]) – also impacted the other types of continuity, for example, in Northern Ontario in Canada, where the shortage of providers distracted from the patient being able to access primary and secondary care services [60]; and in Belgium, where physicians encountered insufficient time to listen to the patient given lack of time [89].

With regard to relational continuity, different identified organizational factors influenced the consistency of physicians in primary and secondary care. An adequate appointment making system (where visits were arranged with their assigned physicians according to their availability), and a small size of the primary care centre (which lacked possibilities to change to a new physician) were considered to result in consistency of physicians of both care levels; whilst the re-organization of patient lists (where patients were assigned to new physicians as it emerged in one study area) distracted from it. Concerning the second dimension of relational continuity – an ongoing patient-physician relationship – the most important influencing factor appeared to be the stability of personnel, as also identified in the meta-synthesis. Furthermore, according to a cross-sectional survey of adult patients in the US and the UK, the length of time

with one physician was a strong predictor of trust in the primary care physician [142]. Results further suggest that a certain frequency or regularity of visits was necessary to be able to establish an ongoing relationship (which in turn was influenced by the gatekeeper system); as also suggested by the results of a qualitative study with type 2 diabetes patients [63] and a cross-sectional study conducted [95] conducted in England.

3.3. Factors related to physicians

Three factors related to physicians were identified to favour continuity of clinical management across the care level: the physician's willingness to collaborate with colleagues reinforced by physicians knowing each other, the physician's commitment to patient care and the primary care physician's technical competence concerning the adequacy of referrals. These factors were considered to avoid duplication of tests and inconsistencies in treatment, promote consultations with other physicians to solve the health problem, and guarantee adequate and timely referrals to secondary care. With relation to continuity of information, one factor, the physician's commitment to patient care, was related to the usage of information from the electronic medical records. To our best knowledge, only the ability to coordinate and the motivation to work cooperatively have been identified in a literature review [67].

Concerning relational, authors from different studies agree that a continuous care between a doctor and a patient, i.e. stability of personnel, does not necessarily lead to an ongoing and caring relationship [138;143] but the quality of the relationship or the patient's consultation experience has a major bearing on how the relationship is both developed and defined [138]. We identified that a combination of three factors favoured the development of an ongoing relationship based on trust, in particular with the primary care physician, and in the case these factors were absent, the patient showed dissatisfaction and sought care with a different physicians. Identified factors related to the adequate medical practice or provided technical quality, effective patient-physician communication, the physician's positive attitude and commitment to patient care (i.e. going beyond merely treating the patient by for example calling the patient to ask about his or her wellbeing). A systematic review of qualitative studies by Ridd et al. [138] concluded that a positive consultation experience (i.e. the patient's personal experience with physicians during consultations), embracing similar influencing factors such as the physician's consultation and communication skills, was necessary to develop an ongoing relationship.

4. Consequences of continuity of care for quality of care

Different consequences of (dis)continuity of care for quality of care and to a lesser degree for the patient health were identified.

With reference to continuity of clinical management, the receipt of conflicting information on diagnosis and treatment from different care providers prevented patients from making progress, resulting in reduced trust in professionals, feelings of loneliness

and, as mentioned by a small number of patients, potential negative health effects (suffering adverse secondary effects when receiving different prescriptions). Lack of access across levels was perceived to be linked to feelings of anxiety (due to long waiting times for secondary care) and the inadequate use of resources (due to duplicating primary care visits). A main consequence of limited information transfer as highlighted by patients was repeatedly having to explain their antecedents, which led to frustration [97;144], or having to store and carry test results to the other care level because information was not shared via computer or up taken by physicians. This consequence – the delegation of responsibilities for information transfer to patients – has been frequently mentioned in literature as a result of discontinuity of information [60;62;83;97]; however, in our results, this element additionally appeared to explain the patient's perception of a lack of information mechanisms put in place, i.e. patients perceived that information was not transferred given the need to retell antecedents. Consistency of personnel was perceived to avoid harmful modifications of the medication plan and duplication of tests and produced feelings of comfortableness and relief. An ongoing relationship facilitated diagnosis making given the physician's accumulated knowledge about the patient, led to fewer unnecessary referrals and enhanced the curing process. Qualitative literature further concluded that an ongoing relationship had a positive impact on the patient's sense of security and resulted in the health professionals taking more responsibility and initiative for following up [58], whilst its absence led to feelings of dissatisfaction [99], helplessness, isolation [83] and vulnerability [145].

5. Contributions to the development of the framework

5.1. Interrelation of types

Although understanding the complexity of continuity of care is crucial to improving it in practice [45], interrelation of types and dimensions of continuity has scarcely been studied. In the adopted framework by Reid et al. [9], their interrelation was mentioned, however, not further analysed. Existent literature particularly focused on studying patients' trade-off preferences in terms of balancing seeing a preferred provider with fast access to healthcare services [51;63;99], but information on how the other types influenced each other remained limited. This thesis contributed to a better understanding of the interrelation of types by identifying two strong links.

First, continuity of information affects continuity of clinical management. For example, communication breakdowns led to unnecessary referrals and repetitions of medical tests, as well as the prescription of incompatible drugs. That specific link has also been identified in the previous literature on continuity of care that cited that medication errors occurred [64] as well as delays in receiving care [60;64;146] when information transfer was hampered.

Second, results suggest that relational continuity played an important role by influencing the other two types, for example consistency of personnel avoided the

duplication of tests or the receipt of different opinions regarding diagnosis and treatment and facilitated diagnosis making because of the physician's accumulated knowledge about the patient. Furthermore, it seems that relational continuity, in particular with their primary care physician, entails further improvements of continuity of clinical management and information *across the care levels*, for instance, patients highlighted that an ongoing relationship with their primary care physician resulted in fewer unnecessary secondary care referrals because the physician showed greater interest in the patient care and thus tried to solve the health problem him-/herself; or patients with an established relationship saw their primary care provider on their own initiative after a secondary care visit for follow-up. A few similar interlinkages between these types were mentioned in the international literature. A qualitative study suggests that an established relationship patient–primary care doctor was associated with fewer barriers to secondary care referral because patients were generally less confident about being referred, or receiving appropriate treatment, when they were unable to see their physician or when the relationship was poor [136]. Quantitative research confirmed that a greater consistency of primary care physicians [55;147] and paediatricians [81] was related with higher coordination of referrals [147], better communication across levels [81] and the primary care physician being informed about care received from specialists [55;81]. Given these findings, special emphasis should be put on establishing and maintaining relational continuity when aiming at achieving continuity of clinical management and information.

5.2. Evidence on patients' capacity for evaluating the services

In contrast to the notion expressed by a few researchers that specific aspects of continuity of care are less salient to health care users [43;50], thus users might not be able to perceive coordinated care with its complex dimensions [51], this thesis provides evidence about the patient's capacity for perceiving continuity across the care levels.

First, the triangulation of perceptions of COPD patients with those of health professionals in the integrated health care networks suggested overall congruency of results; with only a few exceptions. Furthermore, perceptions of patients attended to in the different healthcare areas were contrasted with those of physicians employed at the same organizations within the framework of the same research project, with equally similar findings of perceptions of both informant groups [148]. Only slight differences were encountered with physicians identifying additional coordination problems to the discontinuity elements mentioned by the patients. Rationales for the few identified conflicting findings across the informant groups could be twofold. First, problems experienced by physicians of the integrated health care networks (such as long waiting times for primary care visits) might not be as relevant to patients who used alternative routes, for example the emergency department, or in non-urgent matters just waited until the primary care physician was available. Thus patients might express some different continuity of care needs. Second, other obstacles in care delivery that were only identified by physicians (e.g. limited information transfer via computer) might not

have an impact on the care itself because the physicians were able to mitigate the problem (e.g. use of informal communication mechanisms).

Second, perceptions of patients from the different study areas were in accordance with the mechanisms for information transfer put in place, i.e. patients perceived limited information sharing in Ciutat Vella of Barcelona, in the area where no shared electronic medical record system was implemented; whilst in the other areas with implemented systems, patients indicated existent continuity of information. Thus, we might infer that patients can actually evaluate the effectiveness of initiatives or mechanisms introduced for better care coordination [49].

6. Limitations

Four limitations to the study warrant consideration.

Firstly, the study population in most qualitative studies published on continuity of care, as identified in the meta-synthesis, referred to patients with chronic conditions (particularly type two diabetes and cancer), thus the sample was skewed to elderly people; hence, perceptions of younger patients were underrepresented in the synthesis.

Secondly, in the multiple-case study of COPD patients attended to at integrated health care networks, data were provided by a group of patients with relatively similar characteristics (elderly male patients) due to the limited number of female patients that responded to the selection criteria and accepted to participate. This might have restricted the discursive variation and excluded any additional elements explaining the perception of continuity of care. Nevertheless, the second study conducted in Catalonia did not focus on any specific disease and patients with different profiles in terms of age, sex, and country of origin composed the study sample to gain variation in the discourse.

Thirdly, according to the inclusion criteria of both studies conducted in Catalonia, only patients who were attended to in both primary and secondary care were selected for the participation in the study in order to be able to analyse continuity of care across the care levels. As a result, patients that received care in only one care level and might have encountered barriers to receiving care in the other care level were excluded from the sample. Emergent problems, in particular regarding the adequacy of referrals across care levels and its timeliness, might have been underestimated.

Finally, the different study areas including the integrated health care networks were selected to embody different services management models of the Catalan NHS, thus to take in an important part of the different contexts. However, the areas included might not represent the whole spectrum of the possible contexts. Therefore, caution should be taken when targeting transferability of results to the whole region of Catalonia.

VII. CONCLUSIONS

The main conclusions of the thesis are:

- Patients are able to perceive continuity of care. They express continuity of clinical management and information across care levels and relational continuity with the primary and secondary care physician by referring to concrete elements describing each of their dimensions.
- Our results suggest that the three types of continuity of care are interrelated; showing two strong links. First, continuity of information affected continuity of clinical management, for example, information transfer avoided repetitions of medical tests. Second, relational continuity with one physician played an important role by influencing continuity of clinical management and information, for instance, an ongoing relationship with their primary care physician resulted in fewer unnecessary referrals.
- Patients served in the Catalan NHS generally perceive the existence of continuity of care, with a few elements of discontinuity identified in all study areas and related to all three types. Only two differences are observed between the study areas, which were limited continuity of information across care levels (insufficient information transfer) in the area where primary and secondary care were managed by different entities and limited relational continuity (inconsistencies of primary care physicians) in two integrated health care networks.
- A number of factors that influence continuity of care related to the healthcare system, the organizations and physicians are identified. Among the factors related to the *healthcare system*, the clear distribution of roles and responsibilities between primary and secondary care physicians was perceived to enhance the continuity of clinical management; nevertheless, the primary care physician's gatekeeper function also emerged to be a distracting factor by extending waiting times or even failing to provide access to secondary care. Among the factors related to the *health care organizations*, care coordination mechanisms (face-to-face meetings) and mechanisms for informal communication (e-mail and telephone) are perceived to improve continuity of clinical management, whereas a lack of doctors worsened waiting times for secondary care. Electronic medical records and co-location of physicians were considered to positively influence information transfer, whilst a lack of doctors contributed to an insufficient usage of clinical data. A small size of the primary care centre and an adequate appointment-making system favoured consistency of personnel, whilst the re-organization of patient lists distracted from it. Some of the organizational factors only appeared in one or two study areas and were less salient in the patients' discourse. Among the factors related to the *physicians*, the primary care physician's technical competence favoured continuity of clinical management (adequate referrals), whilst the willingness to collaborate and

the commitment to patient care influenced both continuity of clinical management and information (its use). The physician's adequate medical practice, positive attitudes and commitment to patient care as well as an effective patient-physician communication enhanced relational continuity (the development of an ongoing patient-doctor relationship).

- Different consequences of all three types of continuity of care for quality of care and the patient's health emerge in the study findings. The lack of continuity of clinical management was linked to an inadequate use of resources, feelings of anxiety and loneliness, potential negative health effects and the patient seeking private health care either in Catalonia or, in the case of foreign nationals, in their country of origin. Continuity of information was related to the adequate use of resources and adequacy of treatments prescribed. Finally, relational continuity resulted in fewer unnecessary referrals, provision of adequate treatment, easier diagnose making, feelings of security and comfortableness and adherence to the treatment plan.

VIII. RECOMMENDATIONS

A number of recommendations for the organization of health services and for future health services research can be derived from the results of this thesis.

1. Recommendations for improving the health care provision

1.1 Recommendations for health policy makers

- The healthcare model based on primary health care, as it is promoted by the Spanish and other NHS, should be further fostered given that it first, favours the receipt of care at the right care level with primary care exercising the gatekeeper function, and second, enhances a clear distribution of responsibilities between primary and secondary care with the primary care physician having the holistic view and comprehensive knowledge about the patient and taking over responsibilities for coordinated their along the care continuum.

1.2 Recommendations for health care managers

- Health care organizations should guarantee that responsibilities between professionals of both care levels are clearly defined to enhance continuity of clinical management. This might be achieved by implementing shared clinical guidelines, healthcare maps or other care coordination mechanisms for the standardization of work processes.
- Health care managers should first, assure that care coordination mechanisms (in particular electronic medical records, face-to-face meetings) and mechanisms for informal communication (use of e-mail and telephone) are implemented adequately and second, guarantee that physicians have sufficient time to use these mechanisms put in place.
- Health care organizations should provide patients sufficient opportunities to see their assigned primary care physician and guarantee that doctors are able to dedicate them enough time during the visit by increasing consultation length and frequency.
- Finally, the patient's perspective of continuity of care should be on the health care managers' agenda and should be taken into account when deciding on implementing strategies that aim to improve coordination of care. Health care managers should require that quality improvement measures include and routinely evaluate continuity of care and is further analysed in-depth. Moreover, they should ensure that continuity is clearly identified as a desirable objective in their organization as a means to improve quality of care; and that patients, as the recipients of care are placed in the centre of their organization model.

1.3 Recommendations for health professionals

- Health care professionals should be commitment to patient care and enter into relationships with patients that go beyond usual contracted obligations but target to provide them with the best care possible [149].
- Physicians, in particular primary care physicians, should try to facilitate the development an ongoing patient-doctor relationship based on trust by providing adequate medical care to patients, developing communication and consultation skills and showing sufficient interest in the patient care.

2. Recommendations for future research

- Future research should continue to refine the framework to obtain a better understanding of the complex multidimensional concept and, in particular, should analyse the interrelation of the three types of continuity of care given that the presence or absence of one type might directly influence the other types.
- The relationship between continuity of care and quality of care warrant specific consideration and should be subject to future research because identified consequences of (dis)continuity of care remain to be limited. Acquiring knowledge about the continuity outcomes would favour a better understanding of its importance in health services research.
- Research on continuity of care should be extended to different healthcare areas located in other autonomous communities in Spain and other countries to address its analysis in different health care systems, types of organizations and populations with different socio-economic characteristics. Analysing continuity of care in different contexts would provide opportunities for better understanding the contextual influencing factors; therefore potential encountered differences. Furthermore, the areas identified with high levels of perception could serve as best practice examples and help to address shortcomings identified in the other areas.
- Future research should focus on analysing specific population groups. Whilst perceptions of patients with different types of conditions have already been subject to analysis, the vulnerable population has been included to a lesser degree, even though they might express specific continuity of care needs. This topic has recently gained importance in the context of the economic crisis and its related high migration across the European countries.
- This thesis focused on the analysis of continuity across care levels given that problems are most likely to arise at key interfaces between primary and secondary care; however errors might also occur when care is delivered by different specialities [8]. Hence, the analysis of continuity at one care level (adopting an intra-level perspective), in particular at the secondary care level, should be targeted in future research since this topic has scarcely been studied.

The analysis might include not only continuity of clinical management and information within secondary care but also relational continuity with the specialist given its potentials to improve the other two types.

- Finally, future research should compare the results of the phenomenon of continuity of care with those stemming from research on care coordination (i.e. studies analysing the perspective of the healthcare system that embrace the point of view of health care managers or professionals) in order to better comprehend the slight differences encountered in the perceptions of some of the elements of continuity of care.

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X. ANNEXES

1. Other publications by the Ph.D. candidate on integration of care

1.1. Articles

Aller MB, Vargas I, Waibel S, Coderch J, Sánchez-Pérez I, Colomé LI, Llopart JR, Ferran M, Vázquez ML. A comprehensive analysis of patients' perceptions of continuity of care and their associated factors. *Int J Qual Health Care*. 2013 Jul;25(3):291-9.

Aller MB, Vargas I, Waibel S, Coderch J, Sánchez-Pérez I, Llopart JR, Colomé LI, Ferran M, Garcia-Subirats I, Vázquez ML. Factors associated to experienced continuity of care between primary and outpatient secondary care in the Catalan public healthcare system. *Gac Sanit*. 2013 May-Jun;27(3):207-13.

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1.2. Reports during research visits

Waibel S, Tello J. Toolkit for the analysis of care integration using the continuity of care approach: background paper on continuity of care and case study methodology. WHO Regional Office for Europe. Copenhagen: 2013

Schang L, Waibel S, Thomson S. Measuring care coordination: health system and patient perspectives. Association of Austrian Social Security Institutions. LSE Health. London: 2013

1.3. Master's thesis

Waibel S. La continuidad entre niveles asistenciales en dos organizaciones sanitarias integradas de Cataluña desde la perspectiva de los pacientes con enfermedad pulmonar obstructiva crónica. Tesis del Máster. Universitat Pompeu Fabra. Barcelona: 2010.

1.4. Presentations at conferences

Aller MB, Waibel S, Vargas I, Vázquez ML, Coderch J, Cots F, Abizanda M, Calero S, Colomé LI, Llopart JR, Farré J. How do doctors and patients perceive coordination and continuity across care levels in Catalonia? *Eur J Public Health* 2015; 25 (suppl.3): 470-1

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2. Instruments for qualitative data collection

2.1. Study 2. Topic guide for patients with COPD attended to in integrated health care networks

Datos del usuario: Nombre, edad, sexo, profesión, organización sanitaria integrada, centro de atención primaria al que pertenece y ubicación

Datos de la entrevista: Lugar, fecha, hora de inicio de la entrevista, hora de finalización de la entrevista

Diagnóstico y trayectoria asistencial (reconstrucción del caso)

¿Desde cuándo padece la enfermedad pulmonar? ¿Cómo descubrió que padecía esta enfermedad? ¿Quién le hizo el diagnóstico? ¿Dónde lo diagnosticaron?

¿A qué servicios de salud suele ir para esta enfermedad? ¿Por qué?

Continuidad de relación

¿Qué profesionales le han tratado la enfermedad de los pulmones? ¿Y cuáles le tratan ahora?

¿Quién es el responsable del tratamiento de su enfermedad? ¿Por qué?

¿Qué le parece su relación con los profesionales del hospital que lo atienden? ¿Qué habría que mejorar? ¿Y con su médico de cabecera? (Si no lo mencionan preguntar sobre: ¿Sabe escuchar? ¿Tiene confianza? Etc.)

¿Su médico de su vida, que más conoce aparte de las enfermedades?

Continuidad de información

Cuando le derivaron, ¿cómo sabía el personal lo que había pasado?

¿Cómo se comunica el profesional que le atiende?

¿El médico de cabecera/especialista le dio algún informe para entregarlo al especialista/médico de cabecera?

Continuidad de la gestión clínica

¿Cómo se piden las visitas?

¿Cómo le parece el acceso a los servicios (atención primaria; atención especializada)?

¿Qué le parece el tiempo que tiene que esperar?

¿Cree que le repiten las pruebas (espirometría, análisis de sangre)? ¿Por qué?

¿Le han realizado cambios en su tratamiento? ¿Por qué?

¿Le parece que el médico de cabecera y los especialistas que le atienden colaboraron entre si/ trabajan juntos? ¿Por qué?

2.2. Study 2. Topic guide for health professionals

Datos del entrevistado: Nombre, profesión, organización sanitaria integrada, paciente atendido

Datos de la entrevista: Lugar, fecha, hora de inicio y finalización de la entrevista

Diagnóstico EPOC y trayectoria asistencial

¿Qué servicios ha proporcionado usted al paciente?

¿Qué profesionales atienden al paciente en el atención primaria/especializada?

¿Cómo es la periodicidad de las visitas y las pruebas en la atención primaria? ¿El paciente es controlado rutinariamente? ¿Y en la atención primaria?

¿Quién es responsable del tratamiento? (¿Hay un gestor de caso?) ¿Quién es?

Continuidad de la gestión clínica

¿Cuál es el procedimiento que debe realizar el paciente para solicitar otro servicio? ¿Qué le parece el acceso a los servicios? ¿Y el tiempo de espera?

¿Existen protocolos y/o guías de práctica clínica compartidas para pacientes con EPOC? ¿Se sigue los protocolos y guías? ¿El protocolo permite cambios de acuerdo con las necesidades del paciente?

¿Qué mecanismos se han utilizado para coordinar diferentes niveles? (circuitos de referencias y contra-referencia, GPC, protocolos, planificación de alta, guía farmacológica compartida, sistema de información, puesto de enlace entre niveles) ¿Qué opina de ellos?

¿Hay un plan de atención (medicación y realización pruebas)? ¿Este plan sirve para la próxima visita o para los otros médicos?

Continuidad de información

¿Cómo se transmite la información dentro de un mismo nivel? ¿Y con los diferentes niveles?

¿Qué información se comparte?

¿Cómo le parece la comunicación entre los diferentes niveles en cuanto al seguimiento de la EPOC? (¿Qué consecuencias tiene para el seguimiento?)

¿Cómo considera el acceso a la información por parte de los profesionales?

Continuidad de relación

¿Cómo es la relación entre el paciente y usted? (¿Cree que hay confianza?)

¿Aparte de la información clínica, que conocimiento tiene usted sobre el paciente?

2.3. Study 2. Guide for the review of COPD patients' clinical histories

Datos de la historia clínica: Nombre del paciente con EPOC, número de historial, organización sanitaria integrada, lugar y fecha

Diagnóstico EPOC y trayectoria asistencial

Fecha diagnóstico y responsable

Servicios sanitarios utilizados:

Periodicidad de las visitas del médico de cabecera

Periodicidad de las visitas del especialista

Número de hospitalizaciones por EPOC

Número de visitas en emergencias

Continuidad de la gestión clínica

¿Existe una periodicidad para la realización de las pruebas?

¿Qué profesionales las pide y quién las hace?

¿Existen duplicidades de las pruebas diagnósticas?

¿Existen duplicidades en la prescripción de medicamentos?

¿Existen protocolos y/o guías de práctica clínica compartidas para pacientes con EPOC?

¿Había cambios en el tratamiento del paciente?

¿Cuánto tiempo tardó desde la derivación del primer nivel hasta la consulta del especialista?

¿Cuánto tiempo tardó desde la derivación de la atención especializada al primer nivel?

¿Cómo es la periodicidad de las consultas? ¿Es requerido rutinariamente?

Continuidad de información

¿La información sobre el paciente es accesible a los diferentes proveedores que participan en la atención del paciente? ¿Qué información se comparte?

¿A través de qué mecanismos o medios está disponible dicha información?

¿Rellenan los documentos de derivación entre niveles? (Inter-consulta)

Continuidad de relación

¿Qué profesionales atienden al paciente?

¿Los profesionales que la atienden cuando es hospitalizada, son los mismos que hacen su seguimiento en consulta externa?

¿Existe un gestor de caso? ¿Qué responsabilidades tiene?

2.4. Study 3. Topic guide for health care users of the Catalan national health system

Fecha, hora de inicio/ finalización, lugar de la entrevista, área de salud, CAP,
Sexo, edad, fecha nacimiento, lugar de nacimiento y tiempo en España/Cataluña,
profesión/ocupación, nivel de estudios, seguro de salud privado;

Estado de salud	<i>¿Cómo se encuentra de salud? ¿Por qué?</i>
Utilización servicios	<i>¿Qué servicios de salud ha utilizado? ¿Para que enfermedades?</i>
Experiencias de la transición entre niveles AP ↔ AE (consulta externa, urgencias y hospitalización)	<i>¿Cómo ha sido su experiencia con los servicios de salud? ¿Su médico de cabecera le ha mandado alguna vez al especialista? ¿Por qué? ¿Cómo fue? ¿El especialista le ha mandado alguna vez al médico de cabecera? ¿Por qué? ¿Cómo fue? ¿Ha sido una vez ingresada? ¿Ha ido una vez a urgencias? ¿Por qué? ¿Cómo fue? ¿Después del alta hospitalaria/urgencias le enviaron a otro servicio? ¿Por qué? ¿Cómo fue?</i>
Accesibilidad de los médicos de la AP/AE	<i>¿Le parece que su MC/especialista es accesible? ¿Por qué? ¿Qué le facilita el uso de los servicios? ¿Por qué? ¿Con qué dificultades se encuentra cuando intenta utilizar los servicios de salud? ¿Qué hace ante estas dificultades?</i>
Responsable de la atención	<i>¿Considera que hay alguien que se responsabiliza/ que es el responsable de su atención (tratamiento)? ¿Quién es? ¿Por qué? ¿Alguien que coordina su atención? ¿Hay algún otro profesional (enfermera, trabajadora socia etc.) que considere importante en su atención? ¿Por qué?</i>
Estabilidad del equipo clínico	<i>¿Le trata siempre el mismo médico de cabecera/especialista? ¿Por qué? ¿Qué le parece?</i>
Seguimiento adecuado	<i>¿Le hacen seguimiento de su enfermedad? (¿Le parece que los médicos le llevan el control de su enfermedad?) ¿Qué profesional lo hace? ¿Cómo?: ¿Hay una regularidad en las visitas en la AP/AE? ¿Qué le parece?</i>
Interrupción del seguimiento y adherencia	<i>¿Hay una periodicidad en realizar las pruebas? ¿Qué le parece? ¿Siempre se produce? ¿Había algún problema? En algún momento se ha interrumpido el seguimiento? ¿Alguna vez no ha seguido con las indicaciones del médico? ¿Por qué (consulta cancelada)? ¿Qué ha hecho en este caso?</i>
Flexibilidad	<i>¿Le han tenido que ajustar el tratamiento en algún momento (ha pedido algún cambio)? ¿Por qué? ¿Qué le parece?</i>
Atención individualizada	<i>¿Le parece que recibe la atención que necesita en la AP/AE? ¿Por qué? ¿Qué hace si no la recibe?</i>

Coherencia de atención (pruebas, medicación, indicaciones, tratamiento)	<p><i>¿Los médicos le recomiendan el mismo tratamiento? ¿Ha recibido alguna vez información contradictoria? ¿Qué información? ¿Qué hizo en este caso?</i></p> <p><i>Cuándo es atendido en otro servicio, ¿repiten las mismas pruebas diagnosticas? ¿Por qué? ¿Qué le parece?</i></p>
Transferencia de información (informes) entre AP/AE	<p><i>¿Cree que el médico de cabecera conoce las indicaciones que le ha dado previamente el especialista antes de que usted se las explique? ¿Y el especialista las del médico de cabecera? ¿Por qué? ¿Qué le parece?</i></p> <p><i>¿Ha tenido que repetir su historia clínica o resultados de pruebas en las consultas de su médico de cabecera/especialista? ¿Por qué? ¿Y en urgencias/hospital?</i></p>
Definición coordinación	<i>¿Qué entiende por una buena coordinación entre los médicos?</i>
Percepción de coordinación y colaboración	<i>¿Cree que la atención está coordinada entre los profesionales que le atienden? ¿Por qué? ¿Le parece que los médicos trabajan juntos? ¿Por qué? ¿Qué mejoraría?</i>
Relación con el médico de la AP/AE	<i>¿Cómo es la relación con su médico de cabecera/especialistas/otros profesionales identificados? ¿Cree que su médico se preocupa por usted? ¿Por qué? ¿Qué se podría mejorar?</i>
Confianza	<i>¿Confía en su médico? ¿Por qué?</i>
Conocimiento de valores y preferencias	<i>¿Cree usted que el médico de cabecera/especialista le conoce? ¿Por qué? ¿Conoce su historia clínica (antecedentes, medicamentos, exámenes realizados) circunstancias personales/necesidades de salud? ¿Por qué? ¿Qué le parece? ¿Qué mejoraría?</i>
Comunicación paciente-médico. Información recibida	<p><i>¿Cómo es la comunicación entre usted y el MC/especialista? ¿El médico le entiende? ¿Y usted al médico? ¿Qué se podría mejorar?</i></p> <p><i>¿Qué le parece la información que le da su MC/especialista? ¿Qué se podría mejorar?</i></p>
Co-responsabilidad y adherencia	<i>¿El MC/especialista le incluye en la toma de decisiones? ¿Qué le parece?</i>