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Problèmes soulevés par le suivi des pathologies chroniques en milieu rural et solutions proposées : étude européenne

Jean-Baptiste Kern

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Université Joseph Fourier – Faculté de Médecine de Grenoble

Année 2015

Problèmes soulevés par le suivi des pathologies
chroniques en milieu rural et solutions proposées.

Etude européenne

European Rural and Isolated Practitioners Association – EURIPA

THESE PRESENTEE POUR L'OBTENTION DU DOCTORAT EN MEDECINE

DIPLOME D'ETAT

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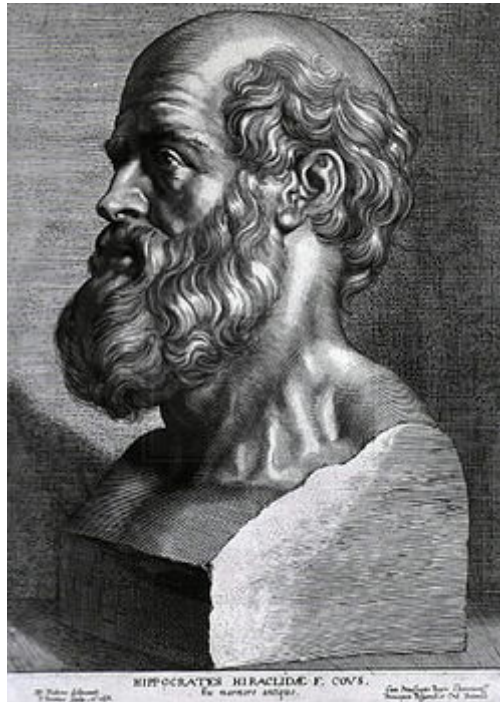
A mes maîtres de stage, actuels et précédents, qui ont su partager avec moi leur goût pour la médecine, générale ou dans sa diversité de toutes les autres spécialités. Pour que le compagnonnage et le désir de transmettre aux plus jeunes existent toujours, grâce à des gens comme vous. Une pensée singulière pour Anne, Claire et Philippe chez qui je suis en stage en Nord-Isère depuis deux semestres.

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Serment d'Hippocrate



*En présence des Maîtres de cette Faculté, de mes chers condisciples
et devant l'effigie d'HIPPOCRATE,*

*Je promets et je jure d'être fidèle aux lois de l'honneur
et de la probité dans l'exercice de la Médecine.*

*Je donnerai mes soins gratuitement à l'indigent et n'exigerai jamais un salaire au
dessus de mon travail. Je ne participerai à aucun partage clandestin d'honoraires.
Admis dans l'intimité des maisons, mes yeux n'y verront pas ce qui s'y passe ; ma
langue taira les secrets qui me seront confiés et mon état ne servira pas à corrompre
les mœurs, ni à favoriser le crime.*

*Je ne permettrai pas que des considérations de religion, de nation, de race, de parti
ou de classe sociale viennent s'interposer entre mon devoir et mon patient.*

Je garderai le respect absolu de la vie humaine.

*Même sous la menace, je n'admettrai pas de faire usage de mes connaissances
médicales contre les lois de l'humanité.*

*Respectueux et reconnaissant envers mes Maîtres, je rendrai à leurs enfants
l'instruction que j'ai reçue de leurs pères.*

Que les hommes m'accordent leur estime si je suis fidèle à mes promesses.

Que je sois couvert d'opprobre et méprisé de mes confrères si j'y manque.

Résumé

OBJECTIFS Réalisation d'un état des lieux des difficultés des médecins généralistes ruraux européens dans le cadre du suivi des patients atteints de pathologies chroniques : récupération des avis, des solutions déjà mises en œuvres, leurs suggestions.

METHODE A été menée une étude qualitative descriptive avec recueil prospectif des données par questionnaire entre février et juillet 2015 auprès de médecins généralistes ruraux européens, avec des éléments additionnels provenant du congrès WONCA Rural d'avril 2015. L'analyse qualitative a été réalisée en triangulation avec la Faculté de Médecine de Izmir, Turquie.

RESULTATS 189 réponses ont été collectées, de 28 nationalités, dont 46% de femmes (IC95 39-53) et 54% d'hommes (IC95 47-61), âgés de 27-76 ans (moyenne 48,7). Les pathologies chroniques les plus fréquentes étaient le diabète pour 82% (IC95 76-87), les pathologies cardiovasculaires 81% (IC95 75-86) et les troubles psychiatriques 71% (IC95 65-77). Les principaux obstacles étaient liés : – Aux patients : non-compliance, problèmes d'éducation, consultations répétées. – Aux maladies : dépistage, prévalence élevée, aspect polypathologique avec dépendance et handicap. – Aux praticiens : manque de temps, impression de non reconnaissance de leur investissement. – Au système de santé : bureaucratie, poids financier, accessibilité aux programmes de rééducation. – Aux aspects pratiques : polymédication, gestion de la distance.

CONCLUSION Au delà des problèmes soulevés, certaines expériences locales positives pourraient être étendues et présentées aux autorités. Cependant il existe aussi des points d'alertes sur lesquels les médecins ruraux devront rester vigilants.

Abstract

OBJECTIVES Purpose was to find out problems encountered by European practitioners in rural areas within their practice connected with care for chronic morbidity patients, and to collect their opinions, solutions already implemented and suggestions.

METHODOLOGY Qualitative descriptive study with prospective data collection was performed from February to July 2015 by questionnaire with additive results from April 2015 WONCA Rural meeting. Survey population was European rural general practitioners (GPs). Qualitative analysis was led jointly with the Faculty of Medicine of Eylul University Turkey.

RESULTS We collected 189 answers from 28 nationalities; age of respondents was: 27-76 years old (mean 48.7). Study group consisted of: 46% female respondents (IC95 39-53) and 54% male (IC95 47-61). Pathologies most frequently related were diabetes 82% (IC95 76-87), cardiovascular diseases 81% (IC95 75-86) and psychiatric disorders 71% (IC95 65-77). Main issues reported were: – Patients non-compliance, education issue, and reiterative consultations. –Diseases owing to problems of screening, a high prevalence and the association of several pathologies with dependence and disability. –Practitioners with mainly a lack of time for GPs and a sense of poor recognition of their involvement. –Health system due to bureaucracy, poverty / costs problems and the access to rehabilitation programs. –Practical difficulties linked with polymedication and distance problems.

CONCLUSION Beyond issues, some positive experiences have to be promoted and would be presented to health authorities in a position paper. However, GPs might keep vigilant on some critical points like limits on their competences.

Introduction

Les patients vivant dans les zones rurales et éloignées sont de plus en plus âgés, et présentent des pathologies chroniques parfois cumulées(1)(2). Une fois passée la question d'un manque de définition commune de la ruralité au niveau international(3), des différences sont retrouvées en termes de handicap, de morbi-mortalité et des caractéristiques propres des maladies selon le milieu de vie, notamment aux dépens de ces régions rurales(4)(5)(6). De plus, les conditions socio-économiques particulières des populations rurales semblent avoir un impact défavorable sur leur état de santé lorsqu'il existe un aspect polypathologique(7).

Les différents systèmes de santé en Europe sont en charge des soins pour les patients porteurs de pathologies chroniques. Les notions de qualité, coût, et d'équité dans les soins sont l'objet actuel d'une étude européenne analysant les systèmes de santé de 34 pays(8)(9), et les premiers résultats viennent d'être présentés à l'OMS*(10).

Par ailleurs, les médecins généralistes (MG) rencontrent des difficultés dans la prise en charge des patients atteints de pathologies chroniques en particulier dans les zones rurales et éloignées. Cette population de patients spécifiques représente une part conséquente de leur activité de soins(11). Pour pallier à ces difficultés, certains MG ont déjà mis en œuvre des solutions dans leur pratique.

Il semble important de faire un état des lieux de ces obstacles dans l'objectif d'avoir une vision globale à l'échelle de l'Europe, et de permettre à EURIPA[†] à l'issue de ce travail de prendre position auprès des autorités sanitaires.

* OMS – Organisation Mondiale de la Santé <http://www.who.int/fr/>

† EURIPA – the European Rural and Isolated Practitioners Association
<http://euripa.woncaeurope.org/>

Objectifs

L'objectif principal de cette étude est la description des problèmes rencontrés par les médecins généralistes européens, exerçant en zone rurale et éloignée, dans les soins délivrés à leurs patients atteints de pathologies chroniques. Le but est également de récolter leurs avis, les solutions déjà mises en œuvre dans leur pratique, ainsi que leurs suggestions pour pallier à ces obstacles et améliorer la prise en charge de cette population.

Matériel et Méthodes

A été conduite une étude qualitative descriptive prospective administrée par un questionnaire informatique LimeSurvey® (logiciel libre d'outils d'études), avec des éléments additionnels provenant d'un atelier sur le thème des pathologies chroniques ayant eu lieu lors du congrès d'avril 2015 de la WONCA[‡] Rural à Dubrovnik, Croatie. Le questionnaire a été construit par consensus entre les membres actifs du groupe de travail « pathologies chroniques » d'EURIPA à partir de données d'une analyse bibliographique (questionnaire joint en annexe).

Les données ont été collectées lors d'une première phase entre le 2 février et le 20 mars 2015, puis secondairement entre le 23 mai et le 6 juillet 2015 afin de compléter les données notamment pour certains pays présentant peu ou pas de réponses.

La population cible était les MG européens ruraux contactés par le groupe de travail « pathologies chroniques » d'EURIPA grâce à une liste d'adresses de courriers électroniques, le soutien de correspondants locaux, et via un « hot topic » (« sujet

[‡] WONCA – Organisation Mondiale des Médecins de Famille
<http://www.globalfamilydoctor.com/>

brûlant ») sur le site web institutionnel d'EURIPA. Les médecins interrogés étaient ensuite joints de façon individuelle par mail pour de plus amples informations, afin de compléter leurs réponses si nécessaire, notamment en cas de questionnaire incomplet.

L'atelier « pathologies chroniques » a eu lieu le 16 avril 2015 pendant le congrès international de la WONCA Rural[§] à Dubrovnik, en Croatie, et a été enregistré par dictaphone (2 sous-groupes, enregistrements audio de 55min chacun). Après une courte présentation des premiers résultats des questionnaires, les participants de chaque groupe ont été invités à débattre et à illustrer leurs propos par des éléments concrets tirés de leurs pratiques. La retranscription des fichiers audio a été réalisée en coopération avec le Centre d'Investigation Clinique du Centre Hospitalier Universitaire de Grenoble.

Ont été exploitées uniquement les données permettant de répondre à la question de recherche. A été utilisée pour l'analyse qualitative une approche inspirée de la « théorie ancrée » (grounded theory). L'analyse qualitative a été réalisée en triangulation avec le Département de Médecine de Famille de la Faculté de Médecine d'Izmir en Turquie. La méthodologie en recherche qualitative nécessitait une analyse indépendante menée par au moins deux chercheurs, avec une mise en commun et comparaison des analyses dans un deuxième temps pour obtenir au final un consensus (triangulation des données).

[§] Plus d'informations sur le congrès <http://woncarural2015.com/>

L'analyse quantitative a été réalisée par le Département de Médecine de Famille et le Département de Technologies Pharmaceutiques de la Faculté de Médecine de Wrocław, en Pologne. Les analyses statistiques ont été effectuées grâce au logiciel Statistica StatSoft 12. Les variables analysées étaient de nature qualitatives (dichotomiques), ordinales et compartimentales.

Concernant l'analyse du nombre de patients vus par jour, du fait d'un nombre trop limité de sujets dans chacun des 12 sous-groupes initialement prévus, une redistribution en trois sous-groupes a été effectuée (moins de 26 consultations par jour, 26 à 40 par jour, plus de 40) afin d'optimiser la significativité des analyses statistiques.

Le test du χ^2 comparé a été utilisé pour la comparaison des variables ordinales. Selon la taille des échantillons, le test du χ^2 avec correction de Yates et le test exact de Fisher ont été utilisés. Le niveau de significativité pour le χ^2 a été fixé à un risque $\alpha = 0,05$.

Pour les variables basées sur des échelles de données, ont été déterminées des statistiques descriptives telles que moyenne, déviation standard, médiane et intervalle singulier de confiance à +/- 95%. La normalité de la distribution des variables a été évaluée par trois différents tests statistiques : test de Kolmogorov-Smirnov, test de Lilliefors, et test de Shapiro-Wilk avec un niveau de confiance $\alpha = 0,05$. L'homogénéité de la variance a été évaluée par les tests de Levene et Brown-Forsyth au niveau de confiance $\alpha = 0,05$. Le niveau de significativité statistique lors de la comparaison de deux moyennes a été évalué – en l'absence de différence significative dans le test de la normalité de la distribution des variables – par un test paramétrique t de Student pour les variables indépendantes, ou un test paramétrique de Cochran-Cox en cas de variances inégales. Dans le cas de variables ne répondant pas au critère de

distribution normale, la comparaison entre deux moyennes a été effectuée par un test U non-paramétrique de Mann-Whitney.

Pour des comparaisons de plus de deux moyennes, ont été employés – selon les résultats de l'évaluation de la normalité et de l'homogénéité des variances – un algorithme d'ANOVA paramétrique ou l'équivalent non-paramétrique, le test ANOVA Kruskal-Wallis avec la médiane. Dans tous les tests, il a été retenu une différence statistique significative dans les comparaisons de moyennes pour un risque $\alpha = 0,05$. Lorsqu'il a été retrouvé une différence significative dans les moyennes du test ANOVA, ont été réalisés plusieurs types de comparaisons post-hoc : NIR Scheffe et Tukey RIR pour des valeurs inégales.

Résultats

Description de la population

189 participants ont été inclus dans l'étude, 102 hommes et 87 femmes, provenant de 28 pays (tableau 1).

L'âge moyen des participants était 48.7 ans. Le médecin le plus jeune avait 27 ans et le plus âgé, 76 ans. La distribution des âges ne répondait pas à une distribution normale au niveau de significativité fixé $\alpha = 0,05$ (tableau 2).

La moyenne d'âge des femmes était d'environ 45 ans, celle des hommes 52 ans. Avec un seuil de significativité $\alpha = 0,05$, il existait une différence statistiquement significative entre les moyennes d'âges des hommes et des femmes (tableau 3).

L'ancienneté d'installation en zone rurale était d'environ 18,37 années. La distribution de la variable ne répondait pas à une distribution normale au niveau de significativité fixé $\alpha = 0,05$.

Dans la population étudiée, les hommes travaillaient en milieu rural de manière significativement plus longue que les femmes. L'ancienneté était de 20,73 années pour les hommes et 15,63 années pour les femmes.

33% des professionnels interrogés ($n=62$, IC95 27-40) recevaient moins de 26 patients par jour, tandis que 34% ($n=64$, IC95 27-41) en voyaient 26 à 40 par jour, et 29% ($n=55$, IC95 23-36) plus de 40 patients par jour.

Il n'a pas été démontré de différence statistiquement significative entre le sexe et le nombre de patients vus par jour ($\text{Chi}^2 = 4,97$; $p = 0,08318$). Cependant, l'analyse de correspondance a montré que les hommes voyaient relativement plus de patients par jour que les femmes.

Il n'a pas été retrouvé de corrélation statistiquement significative entre l'âge des participants et le nombre de patients vus par jour au niveau de significativité fixé $\alpha = 0,05$.

Le nombre médian de patients tous motifs confondus vus en visite à domicile par jour était de 2 patients (min-max 1-45, inf-sup quartile 1-3). Le nombre médian de patients avec une pathologie chronique consultant au cabinet par jour était de 15 patients (min-max 0-200, inf-sup quartile 10-25).

La durée moyenne d'une journée de consultation en milieu rural était de 8,73 heures environ. La distribution de la variable ne répondait pas à une distribution normale au niveau de significativité fixé $\alpha = 0,05$.

Tableau 1 Population

Participants n=189

	n	%(IC95)	p-value (le cas échéant)		n	%(IC95)	p-value (le cas échéant)
Sexe				Patients/jour			
Hommes	102	54 (47-61)		Moins de 26	62	33 (27-40)	
Femmes	87	46 (39-53)		26 à 40	64	34 (27-41)	
<i>Total</i>	189	100		Plus de 40	55	29 (23-36)	
				Manquant	8	4 (2-8)	
				<i>Total</i>	189	100	
Age (années)							
20-30	7	4 (2-7)					
30-40	44	23 (18-30)					
40-50	48	25 (20-32)					
50-60	64	34 (24-40)					
60-70	24	13 (9-18)					
70-80	2	1 (0-4)					
<i>Total</i>	189	100	p=0,000036 *				

* Normalité évaluée par un test de Shapiro-Wilk à un seuil de significativité $\alpha = 0.05$

Tableau 2

Population 2

Participants n=189

	Moyenne (Médiane)	Dev Std	Inf-Sup quartiles (Min-Max)	p-value*
Age (années)	48.74 (49)	10.86	39-58 (27-76)	0.00036
Ancienneté en milieu rural (années)	18.37 (18)	10.88	8.5-27 (1-45)	0.00003
Visites à domicile par jour	2.66 (2)	4.08	1-3 (1-45)	<0.00001
Patients avec pathologie chronique vus au cabinet par jour	19.08 (15)	19.19	10-25 (0-200)	<0.00001
Patients avec pathologie chronique vus en visite par jour	2.57 (1)	4.75	1-2 (0-50)	<0.00001
Enfants vus au cabinet par jour	6.87 (5)	7.17	2-10 (0-40)	<0.00001
Heures travaillées par jour (heures)	8.74 (8)	2.29	7-10 (5-24**)	<0.00001

* Normalité évaluée par un test de Shapiro-Wilk à un seuil de significativité $\alpha = 0.05$

Tableau 3

Tests statistiques

Participants n=189

Mann-Whitney U Test	Moyenne Hommes	Moyenne Femmes	Z-ajusté	p-value
Age vs Sexe	51.87	45.06	4.32	< 0.01

$\alpha = 0.05$

Mann-Whitney U Test	Moyenne Hommes	Moyenne Femmes	Z-ajusté	p-value
Ancienneté d'installation vs Sexe	20.73	15.63	3.12	< 0.01

$\alpha = 0.05$

Chi ²	Chi ²	p-value
Nbre de patients vus par jour vs Sexe	4.97	0.08

ANOVA Kruskal-Wallis Test	Code	Valid N	Somme des rangs	Moyenne des rangs
Plus de 40	101	55	4516.000	82.1091
26 à 40	102	64	5606.500	87.6016
Moins de 26	103	62	6348.500	102.3952

Nbre de patients vus par jour vs Age	H (2, N=181) = 4.7907	p- value	0.0911
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Description de l'activité des médecins généralistes

Les pathologies les plus fréquemment rencontrées (tableau 4) par les répondants étaient : le diabète pour 82% des répondants (n=155, IC95 76-87), les pathologies cardiovasculaires pour 81% (n=153, IC95 75-86) et les troubles psychiatriques 71% (n=135, IC95 65-77). Les médecins généralistes (MG) relevaient les facteurs de risques suivants : l'alcool pour 60% (n=114, IC95 53-67) ou la pauvreté pour 48% (n=90, IC95 51-55).

Pour leurs sources de revenus, les MG ruraux européens recevaient des financements divers provenant : de services de santé nationaux ou régionaux pour 51% d'entre eux (n=97, IC95 44-58), de dispositifs de capitation pour 32% (n=61, IC95 26-39) ou de paiement direct par les patients pour 28% (n=53, IC95 22-35).

Ils travaillaient pour la plupart à plein temps (83% n=156, IC95 76-87). Certains d'entre eux présentaient un engagement universitaire (20% n=37, IC95 15-26). Un seul participant travaillait en milieu hospitalier (1%, IC95 1-3).

En milieu rural, les MG travaillaient en collaboration avec des infirmières pour 67% d'entre eux (n=126, IC95 60-73), avec d'autres MG pour 44% (n=84, IC95 38-52) tandis que 17% travaillaient seuls (n=32, IC95 12-23). Leur activité principale était partagée à la fois entre le domaine clinique, comme la pédiatrie pour 59% (n=111, IC95 52-66), une participation aux gardes pour 33% (n=62, IC95 27-40), et le domaine technique tel que la possibilité de réaliser un électrocardiogramme pour 75% (n=142, IC95 68-81) ou des analyses biologiques sur place pour 42% (n=79, IC95 35-49).

Concernant leur équipement électronique, la plupart d'entre eux étaient équipés d'un logiciel métier (76% n=143, IC95 69-81), et recevaient les résultats en ligne de laboratoires (67% n=126, IC95 60-73). Les MG participants signalaient échanger entre eux par voie électronique pour 32% d'entre eux (n=60, IC95 26-39). L'usage d'applications médicales sur smartphone était décrit chez 36% (n=68, IC95 29-43).

Tableau 4 (partie 1)

Activités

Participants n=189

Missions et sources de revenus des MG	n	%(IC95)	Comment les MG travaillent	n	%(IC95)
Paiement direct	53	28 (22-35)	A plein temps	156	83 (76-87)
Mandat	10	5 (3-9)	A temps partiel	20	11 (7-16)
Capitation	61	32 (26-39)	Autre métier*	20	11 (7-16)
Garde barrière	32	17 (12-23)	Activité hospitalière	1	1 (1-3)
Services de santé nationaux or régionaux	97	51 (41-58)	Investissement universitaire	37	20 (15-26)
Assurances privées	18	10 (6-15)	Investissement dans la formation continue	34	18 (13-24)
Autre*	6	3 (1-7)			

*pas de détails supplémentaires

*comme interniste dans une clinique privée ; au Ministère de la Défense ; 60% chirurgie 40% enseignant dans un programme régional ; médecin coordinateur dans une maison de retraite ; PDG d'un réseau de praticiens ; médecine du travail ; service d'urgence ; dans une ONG en banlieue urbaine

Equipes en milieu rural	n	%(IC95)	Facteurs de risque	n	%(IC95)
Activité isolée	32	17 (12-23)	Pollution	33	17 (13-24)
Groupe de MG	84	44 (38-52)	Pauvreté	90	48 (41-55)
Infirmières	126	67 (60-73)	Drogues	47	25 (19-32)
Sages-Femmes	34	18 (13-24)	Alcool	114	60 (53-67)
Kinésithérapeutes	28	15 (10-21)	Risques professionnels*	36	19 (14-25)
Psychologues	11	6 (3-10)	Autre**	22	12 (8-17)
Autre profession de santé*	44	23 (18-30)			
Autre spécialité**	25	13 (9-19)			
Travailleurs sociaux	23	12 (8-18)			
Autre***	10	5 (3-9)			

*infirmière psychiatrique ; assistants médicaux ; orthophoniste ; dentiste ; diététicienne , ostéopathe

**Pharmacien ; 3 autres spécialistes ; 1 pédiatre partagé avec une autre maison de santé en zone rurale

***des infirmières dans un bâtiment proche ; secrétariat ; manager, une réceptionniste ; une autre personne ; assistants médicaux éventuels

*fermiers ; marins , pêcheurs , volontaires de secourisme en mer ; amiante ; mineurs , charpentiers , artisans ; travailleurs manuels

**Tabac ; centrale nucléaire située à moins de 30km ; eau salée ; population très âgée, beaucoup vivent seuls ; travailleurs agricoles ; chômage

Tableau 4 (partie 2)

Activités	n	%(IC95)		n	%(IC95)
<i>Activités cliniques</i>			<i>Instruments</i>		
Gardes / Permanence des soins	62	33 (27-40)	Electrocardiogramme	142	75 (68-81)
Consultations en urgence	60	32 (26-39)	Explorations fonctionnelles respiratoires	74	39 (32-46)
Suivi de grossesse / Gynécologie	57	30 (24-37)	Echographie	38	20 (15-26)
Accouchements	4	2 (1-5)	Analyses biologiques	79	42 (35-49)
Thérapies comportementales	23	12 (8-18)	Radiologie	18	10 (6-15)
Pédiatrie	111	59 (52-66)	Autre*	45	24 (18-30)

*médecine de famille ; médecine du travail pour 30 patients ; psychiatrie ; angiologie, surveillance anti-vitamine K ; dermatologie ; soins communautaires ; santé des femmes ; médecine des voyageurs ; médecin des marins, secours en mer, and vaccinations ; mésothérapie ; oligothérapie ; soins palliatifs ; médecine manuelle / chiropratique ; traitements par perfusion ; chirurgie (mineure) ; prévention des risques ; sevrages alcooliques ; ostéopathie

Environnement électronique	n	%(IC95)		n	%(IC95)
Logiciel métier	143	76 (69-81)	Lien entre MG	60	32 (26-39)
Lien avec l'hôpital	51	27 (21-34)	Lien avec d'autres spécialistes	53	28 (22-35)
Lien avec laboratoires d'analyses biologiques	126	67 (60-73)	Usage d'applications sur smartphone	69	36 (29-43)
Lien avec services sociaux et sanitaires	25	13 (9-19)	Usage de systèmes d'aide à la décision	28	15 (10-21)
Lien avec les patients	38	20 (15-26)	Autre*	12	7 (4-11)

*lien avec le système informatique national ; bases de données ; références/recommandations ; soins palliatifs ; pas de reconnaissance de la e-médecine dans certains pays ; pas de moyens informatiques

Pathologies chroniques	n	%(IC95)		n	%(IC95)
Diabètes	155	82 (76-87)	Cancers	132	70 (63-76)
Pathologies cardiovasculaires	153	81 (75-86)	Maladies infectieuses (par ex. VIH)	68	36 (29-43)
Pathologies rhumatismales	132	70 (63-76)	Troubles musculo-squelettiques	132	70 (63-76)
BPCO	131	69 (62-75)	Troubles psychiatriques	135	71 (65-77)
Asthme	126	67 (60-73)	Autre*	19	25 (19-32)
Accidents Vasculaires Cérébraux	100	53 (46-60)			

*Obésité ; troubles ophtalmologiques (glaucome, cataracte) ; hypertrophie de prostate ; dermatologie ; drogues et alcool ; insuffisance rénale ; Douleurs chroniques et troubles fonctionnels ; troubles neurologiques, sclérose en plaques, maladie d'Alzheimer, Maladie de Parkinson and autres démences ; dyslipidémies ; troubles digestifs ; polyopathologies ; maladies infectieuses courantes ; contraception ; troubles thyroïdiens ; infections respiratoires ; I10.9 ; "fatigue" ; allergies ; I25.9 ; blessures/traumatologie ; D84 ; maladies auto-immunes ; troubles du sommeil (par ex Syndrome d'Apnées du Sommeil) ; maladies ORL ; problèmes gastriques (ulcères etc.) ; D98 ; Anémies ; Certificats administratifs ; comportements à risque ; pauvreté

Analyse qualitative

Principaux obstacles

Cinq principaux thèmes se sont dégagés de l'analyse des questionnaires en ce qui concerne les obstacles retrouvés dans la prise en charge des patients atteints de pathologies chroniques. Premièrement, les problèmes en lien avec les patients et leurs proches. Deuxièmement les difficultés en lien avec les praticiens eux-mêmes et le parcours de soins. Ensuite ceux liés aux pathologies chroniques et l'aspect polypathologique. Puis les problèmes liés au système de santé et son organisation. Et enfin ceux liés à des difficultés d'ordre pratique ou géographique.



Figure 1 principaux thèmes

Patients et leurs proches

Dans la plupart des cas, les participants ont mentionné comme principale difficulté la non-compliance dans la prise des traitements ou la modification des habitudes de vie (« adhérence », « observance » sont utilisés comme synonymes dans les questionnaires). Cet élément est expliqué par les praticiens principalement par le nombre de médicaments à prendre quotidiennement (« beaucoup trop de médica

ments à prendre »). De plus, les MG européens ont évoqué comme autres explications le manque de temps (accordé aux patients pour des explications, mais aussi pris par les patients eux-mêmes), les « prix en constante augmentation » des médicaments, mais aussi « la vieillesse », source en elle-même de « confusion ». Les MG ont soulevé dans leurs réponses le « manque de motivation » (ou « de coopération ») de leurs patients. Il n'y a « pas de volonté pour les traitements ». Les patients atteints de pathologies chroniques « ne prennent pas les traitements tels que prescrits ». Les MG concluaient à un réel problème de communication avec les patients atteints de pathologies chroniques.

Le second obstacle décrit était lié à l'éducation des patients, en particulier leur éducation médicale ou thérapeutique (« pas de responsabilité », « faible niveau d'instruction en santé »). De plus, les praticiens se plaignaient d'un manque de savoir vivre et de compétence de leurs patients : « les patients ne viennent pas aux rendez-vous régulièrement » ou « les patients sont incompetents ».

En ce qui concerne le cadre de vie des patients, les MG relevaient des « mauvaises habitudes » de vie (notamment cités : « obésité », « activités sédentaires », ou « stress »), mais aussi des « difficultés pour comprendre l'importance et les conséquences d'habitudes de vie saines ». Les participants soulignaient également les difficultés liées à l'isolement et la solitude (en particulier pour les personnes âgées : « cela empire avec une population qui vieillit »), et l'impact que cela peut avoir pour les soins à domicile et les soignants.

Enfin, une vision partagée sur plusieurs questionnaires était en lien avec les motifs de consultation : motifs infondés et consultations réitératives étaient également source de difficultés pour les praticiens. « Les patients viennent souvent sans raisons,

juste pour une nouvelle ordonnance ». A l'opposé, certains MG regrettaient un « manque de bilans réguliers ».

Praticiens et parcours de soins

Le temps et le manque de temps étaient rapportés de façon consensuelle comme étant source de difficultés. Les participants ont ainsi fait part de l'obstacle que représentait pour eux la gestion du temps, notamment lié à « une durée excessive des consultations », à un nombre important de patients (« trop de patients par jour », et avec « trop de maladies »). « Les tâches administratives » et « la fragmentation du temps dédié aux soins » étaient également impliquées dans cette difficulté. Cela impactait également négativement leurs possibilités de formation continue. Les faibles effectifs de MG en milieu rural étaient mis aussi en lien avec cette problématique de gestion du temps (« manque de praticiens »). Sur une note pessimiste, un des médecins participants concluait : « le burn-out est sans cesse imminent ».

Concernant le parcours de soins, les médecins ruraux, dans le cadre des soins multidisciplinaires, soulignaient les difficultés rencontrées avec les autres spécialistes : en termes de « faible coopération », et de « difficultés pour avoir un avis spécialisé » (principalement dûes aux délais d'attente : « un très long moment est nécessaire pour pouvoir accéder à un spécialiste »). En ce qui concernait la coordination des soins, les MG rencontraient des obstacles du fait d'un « manque de coordination d'équipe » avec tous les professionnels en charge des patients atteints de pathologies chroniques. Ils signalaient ne pas être à l'aise pour organiser le « suivi entre les soignants », et parfois même se sentaient dépassés pour « garder une vue d'ensemble ». La place même du patient au sein de son parcours de soins n'était pas évident non plus : certains participants répondaient que « les soins ne sont pas centrés sur le patient ». De plus,

du fait de « la situation rurale », des notions d'accessibilité rentraient aussi en jeu dans la gestion du parcours de soins.

D'autres questionnaires recueillis faisaient allusion à la notion de valeur du travail des MG ruraux, et de la reconnaissance de leur investissement. Que ce soit sur le plan moral ou financier, ils notaient ainsi « une absence de reconnaissance de leur travail », « un manque de moyens », des difficultés pour leur propre retraite et une reconnaissance financière inadaptée en regard du temps consacré à la prise en charge des patients atteints de pathologies chroniques, ainsi qu'en ce qui concernait le temps dédié pour leur formation continue. Certains médecins estimaient également que les compétences des MG étaient limitées du fait « d'obstacles instaurés pour la prescription de certains médicaments », alors que d'autres participants considéraient que ces problèmes trouvaient leur origine dans les limites de « la confiance accordée par les autorités de santé ».

Maladies et polypathologie

Un des problèmes les plus relevés par les participants était l'association de plusieurs pathologies chroniques. Ceci entraînait un certain nombre de difficultés au niveau des traitements (« traitements complexes », « possibilités réduites de traitements »), un impact notable sur le plan social (« les patients ne peuvent pas travailler et ceci entraîne un handicap social »). Ce phénomène était décrit comme étant exacerbé dans la population des personnes âgées, en particulier lorsque survenaient des troubles cognitifs (« beaucoup sont des patients plus âgés sans aidants et avec des troubles cognitifs, vivant seuls ou avec leurs conjoints tout aussi âgés »).

L'impact des pathologies sur la vie quotidienne était décrit comme conséquent par les MG, entraînant une « réduction de la qualité de vie » pour les patients. Ceci était illustré par des notions telles que « handicap », « dépendance » et « invalidité ». De même, « l'autonomie » des patients était décrite comme impactée par les pathologies chroniques, notamment du fait de restrictions sur le permis de conduire, pour des pathologies telles que l'épilepsie par exemple ou en cas de traitements psychotropes. De plus, « définir et maintenir un plan de soins » dans ce cadre polypathologique était rapporté comme un enjeu, notamment pour les soins de fin de vie.

Le dernier thème prédominant relevé par les participants à propos des maladies elles-mêmes était celui de la prévention. Avec des pathologies chroniques à « forte prévalence », le dépistage était apparu comme un point-clé, et le principal obstacle relevé à ce propos concernait le manque d'intérêt des patients. D'un autre côté, les MG notaient dans leur pratique un poids important des addictions, en particulier du tabagisme et de ses conséquences, de la consommation d'alcool (avec « des alcools de faible qualité bus régulièrement »), des drogues et autres problèmes de dépendance. La question de la surcharge pondérale était aussi soulignée comme problématique par plusieurs praticiens européens.

Système de santé et son organisation

Un nombre important d'items ont été identifiés autour de questions financières. La pauvreté et les problèmes sociaux en étaient les principaux. En ce qui concerne la pauvreté, celle-ci a été décrite comme « diminuant les chances d'avoir une balance favorable avec les pathologies chroniques ». De mauvaises conditions sociales comme « de faibles revenus » ou « des petites retraites » ont été associées à une plus

grande difficulté d'accès au système de santé pour des populations particulières telles que les paysans, les roms / gitans ou les retraités (notamment « ceux qui travaillaient dans l'agriculture»). Les MG ont également fait part de leurs regrets à propos des « ressources limitées » pour la médecine (« pas d'argent pour la médecine »), et des « coupes budgétaires dans les dépenses de santé » notamment liées à la crise économique. Ceci a pu se traduire pour certains praticiens en termes de difficultés « pour acheter des équipements spécifiques tels qu'un appareil à échographie ou un électrocardiographe ».

De plus, les coûts pour les dépenses de santé étaient mentionnés soit comme étant élevés (« coût élevé comparé aux revenus ») ou comme variables selon les pays, posant des difficultés dans « l'accès au diagnostic » (pour réaliser des examens sanguins ou autres explorations) ou pour acheter des médicaments (« les dernières nouveautés de médicaments à prix élevé »). Le remboursement était mentionné aussi avec « une part variable restant à charge du patient », ce qui interpellait les médecins ruraux au sujet du « manque d'assurances santé / médicales ».

En matière de soins dans le système de santé actuel, les MG identifiaient d'autres obstacles spécifiques à la paperasserie et autres « barrières bureaucratiques », prenant une part « croissante » de leur travail quotidien. A ce sujet, un des éléments décrits concernait « le contrôle de leurs prescriptions », par exemple via des autorisations spécifiques délivrées par les assurances santé pour certains antidiabétiques. Ceci entraînait des difficultés dans les relations avec les organismes d'assurances, notamment les compagnies privées. Les participants au questionnaire concluaient en général à un état de « faillite du système de santé », notamment du système public dans lequel – dans certains pays – n'exercent que « trop peu de praticiens ».

Lorsqu'ils étaient interrogés à propos de l'accès aux programmes de rééducation, les participants au questionnaire répondaient que cet accès était tout d'abord limité par la motivation des patients, du nombre existant de programmes et du nombre de participants, du coût de ces programmes, et des conditions ou accès spécifiques pour certaines maladies chroniques. Les centres de rééducation étaient parfois éloignés des zones rurales (« distance jusqu'au centre de rééducation »), avec de longues listes d'attentes. En outre, certains médecins commentaient que ces programmes « n'étaient pas efficaces pour le patient » et « non adaptés aux problèmes ruraux ». Pour ce qui était des soins à domicile, étaient relatées également des difficultés d'accès, par exemple « pour avoir de la kinésithérapie à domicile ».

Une vision partagée par l'ensemble des médecins tout au long des questionnaires était que « les zones rurales sont laissées de côté » dans le système de santé actuel. Ce sentiment a pu être exprimé aussi par les MG ruraux ayant l'impression « de travailler plus dur qu'en ville ».

Aspects pratiques et géographiques

Le premier élément d'ordre pratique décrit concernait les médicaments. Les praticiens soulevaient à de nombreuses reprises le problème central de la polymédication : « trop de médicaments », présentant des effets indésirables et « des interactions médicamenteuses ». Leurs difficultés se portaient aussi sur le choix « du bon traitement », en accord avec les recommandations, et dans l'idée d'arriver « à un traitement efficace ». En outre, selon les pays certaines prescriptions devaient être initiées par un spécialiste. Comme notion ayant émergé de l'analyse des données, apparaissait également la question des médicaments génériques, avec son corollaire « le temps dédié aux explications autour de ces médicaments génériques ». Par

ailleurs, étaient décrites d'autres problématiques autour des cessations de traitement, qu'elles fussent dues à « des malentendus, au coût, à des effets secondaires », mais aussi aux « ruptures de stock » de certains produits.

L'autre thème principal dans les éléments d'ordre pratique était l'accessibilité aux régions rurales et éloignées. Les participants faisaient part des difficultés d'accès au MG, à d'autres spécialistes, aux investigations, ou aux services sanitaires et sociaux. La distance était la raison principale, avec une « longue distance jusqu'au cabinet du médecin » et par ailleurs pour les patients également « un manque de service de proximité ». Qui plus est, « les spécialités techniques sont souvent inaccessibles ». Concernant les soins à domicile, « peu de prestations sont réalisées chez le patient ». « Sans voiture, ni bus » dans certaines zones rurales, le transport (ou plutôt le manque de moyens de transport) était ciblé également comme une potentielle source de difficulté, plus particulièrement pour la population âgée. Ceci avait pour conséquence un accroissement de la perception de « l'isolement des patients et des praticiens », et de la « solitude » des patients.

Dans quelques questionnaires étaient abordés les obstacles liés aux infrastructures de réseau telles « les coupures de courant et d'internet ».

Expériences positives

Patients et leurs proches

En termes de solutions déjà instaurées dans leur pratique, les MG présentaient dans les questionnaires des moyens pour améliorer l'éducation des patients. Le diabète était la maladie pour laquelle a été adapté un grand nombre de programmes d'éducation thérapeutique dans la plupart des pays européens, sous la forme « d'écoles du diabète ». Pour améliorer l'autonomie des patients, certains pays

mettaient aussi en place des « programmes pour le dos » à destination des patients présentant des troubles musculo-squelettiques aigus et chroniques. D'autres programmes similaires étaient mentionnés pour la BPCO. Ceci a pu être instauré grâce à des infirmières spécifiques telles que celles de l'association « ASALEE » (Action de Santé Libérale En Equipe) en France, dont l'activité est dédiée à l'éducation des patients atteints de pathologies chroniques ainsi qu'au dépistage de ces pathologies.

Pour améliorer l'observance aux traitements, les praticiens relevaient notamment comme solution l'emploi de « médicaments 2 en 1 ». Avec l'aide de l'informatique et de leur logiciel métier, certains médecins expliquaient pouvoir « calculer le meilleur prix pour une prescription » et consulter « l'historique médicamenteux électronique du patient ».

Concernant la communication avec les patients, les praticiens utilisaient « des flyers pour les patients » ou à « des affiches » pour promouvoir des messages de santé publique. Les médecins participaient aussi à « des programmes d'évaluation de l'état de santé de la population » pour mieux comprendre et connaître leur zone d'activité.

Praticiens et parcours de soin

Dans l'idée d'avoir un meilleur accès aux spécialistes, en premier lieu, les MG interrogés essayaient de limiter la demande d'avis spécialisés au strict minimum et indispensable en particulier « pour des problèmes qui pourraient être gérés par un MG ». Quand l'avis d'un spécialiste était nécessaire, certains signalaient envoyer d'abord « un fax pour obtenir un rendez-vous rapide ». Dans cette idée d'optimisation de l'accès aux spécialistes, les MG développaient dans certains pays des liens plus

étroits avec des spécialités spécifiques comme la psychiatrie ou les centres de rééducation.

Concernant leur réseau de soins de santé, certains participants indiquaient la création de réseaux personnels spécifiques dédiés aux soins primaires, « centrés sur la prise en charge des patients à domicile ». Ceci nécessitait une bonne communication entre tous les professionnels de santé et sociaux, en particulier autour des personnes âgées. En Espagne, annuellement, a lieu une conférence pluri-professionnelle au sujet des pathologies chroniques, de façon à définir les objectifs de prise en charge pour l'année suivante (avec la participation des médecins, des infirmières, des travailleurs sociaux et des associations de patients). En France, des structures appelées MAIA (Maison pour l'Autonomie et l'Intégration des malades d'Alzheimer ^{**}) étaient décrites, facilitant la prise en charge des problèmes sociaux des patients âgés atteints de pathologies chroniques.

Un nombre de solutions détaillées concernait l'équipe de soins et la gestion du cabinet aussi bien sur le plan de la gestion de l'emploi du temps avec « des consultations sur rendez-vous », des créneaux « de 15 minutes par patient », que sur le plan matériel avec l'acquisition d'équipements, tels qu'un échographe (activité d'échographie rendue possible grâce à « un contrat distinct » avec l'assurance maladie nationale en Roumanie). Par ailleurs, certaines solutions remodelaient l'équipe de soins elle-même : l'emploi « d'infirmières praticiennes » au Royaume-Uni, ou la construction de « maison médicales de santé » en France, réunissant plusieurs praticiens et professionnels de santé.

^{**} Devenu récemment : Méthode d'Action pour l'Intégration des services d'aide et de soins dans le champ de l'Autonomie (loi Vieillesse septembre 2014) - <http://www.cnsa.fr/parcours-de-vie/maia>

Lorsqu'ils étaient interrogés sur les meilleurs moyens d'améliorer la qualité des soins, les participants faisaient référence à la « médecine basée sur les faits » (« evidence-based medicine »), aux recommandations, aux cercles de qualité et aux « groupes d'études et d'analyses des erreurs » pouvant les y aider. Des exemples plus détaillés étaient relatés par les médecins anglais avec le système de paiement à la performance Quality and Outcomes Framework (QOF^{††}) ou par les MG allemands via les recommandations de leur société savante Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin (DEGAM^{‡‡}).

Maladies et polypathologie

Quelques éléments étaient cités dans le cadre de la prévention, ainsi que pour l'amélioration du parcours de soins du patient, notamment pour les patients atteints de cancer. Ainsi, en Norvège venait de démarrer un programme « pour raccourcir et optimiser le bilan complet des patients avec une suspicion de cancer ».

Les réponses des MG se concentraient aussi autour du dépistage des pathologies chroniques en particulier « du diabète et de l'hypertension », « des facteurs de risque cardiovasculaires », « des pathologies respiratoires chroniques et la tuberculose » ou « des cancers ». D'autres participants mentionnaient être investis dans des programmes de « sevrage tabagique », ou dans la prévention des chutes grâce à la rythmique Jacques Dalcroze^{§§} (en Suisse).

Au sujet des patients âgés, certains médecins signalaient avoir rejoint des réseaux médicaux et administratifs qui participent à « réduire significativement la charge du praticien » afin d'améliorer leur pratique.

^{††} <http://www.hscic.gov.uk/qof>

^{‡‡} <http://www.degam.de/guidelines.html>

^{§§} <http://www.dalcroze.ch/rythmique-geneve-quoi/>

Système de santé et son organisation

En ce qui concerne des actions positives dans le domaine économique, les répondants soulignaient le bénéfice que peut représenter « un PIB plus élevé » (notamment en Roumanie) ou d'autres actions touchant le prix des médicaments.

En Suède, pour améliorer les relations avec les autorités, étaient instaurées des « tables rondes » – auxquelles participent les médecins – pour évoquer des sujets sociaux tels que « les listes de malades » (avec invalidité et donc impossibilité de travailler) et « le chômage ».

Une organisation expérimentée dans certains pays concernait l'articulation de réseaux spécifiques de soins primaires, avec des « centres régionaux » et permettant un lien optimisé « entre l'hôpital et les soins primaires » notamment en Espagne.

Aspects pratiques

Une vision partagée dans de nombreux questionnaires était l'apport des technologies dans l'amélioration de la pratique des MG. Ainsi en Allemagne où les examens biologiques sont réalisables directement au cabinet, « l'ajout d'une nouvelle centrifugeuse » a pu contribuer à réduire certains problèmes d'accessibilité aux examens complémentaires. En Turquie, un système informatique centralisé appelé « AHBS » (acronyme turc pour Système d'Information en Médecine de Famille) permettait aux médecins de soins primaires, aux infirmières et aux sages-femmes de mettre en commun et d'enregistrer sur un même dossier leurs actions concernant notamment la vaccination et les prescriptions.

En ce qui concerne l'accès au système de santé, les MG ruraux au Royaume-Uni décrivaient l'envoi « d'infirmières et d'assistants médicaux pour voir les gens à

domicile », pendant qu'en Hongrie « les spécialistes sont transportés jusqu'aux villages pour dépister la population ». En Irlande, un participant relatait des initiatives locales « avec un bus pour aller recueillir les patients », en particulier pour « les personnes âgées vivant seules », leur permettant de se rendre dans un « centre d'action médico-social d'accueil de jour ». La notion de meilleur accès intégrait aussi pour certains médecins en Autriche la constitution « d'une liste d'institutions » et de leurs coordonnées (dans le domaine social, psychiatriques, des associations...).

Il est à noter cependant qu'un médecin français mettait en avant dans sa réponse de meilleures conditions d'exercice en milieu rural : « les autres professionnels de santé du secteur sont parfaitement connus », les difficultés rencontrées étaient limitées grâce « à la contribution des ordinateurs et de la technologie » et le praticien bénéficiait également « de meilleures conditions de vie et une meilleure qualité dans les relations avec les patients ».

Suggestions

Aucune suggestions

Un petit nombre de praticiens européens interrogés répondait plutôt pessimistes qu'il n'avait aucune suggestion : « nos difficultés sont juste croissantes », ou dans un registre fataliste : « personne ne nous écoute ».

Certains médecins faisaient part de propositions non détaillées pouvant être qualifiées de vœux pieux : « avoir plus d'argent », « changer le système de santé » ou « avoir de nouvelles lois » sans plus de précisions.

Praticiens et parcours de soins

La plupart des participants présentaient des suggestions concernant leur propre pratique, notamment sur le sujet de la gestion du temps. Pour disposer de plus de temps, ils proposaient en premier lieu « de diminuer la bureaucratie » par « moins de paperasserie », « moins de travail de bureau », ou « moins de documents » à remplir. Par ailleurs, ils suggéraient « de réduire le nombre de patients vus par jour » et « d'avoir plus de temps avec chacun des patients », en particulier ceux atteints de pathologies chroniques et ceux en fin de vie.

Le second élément principal ressortant de leurs suggestions sur leur pratique portait sur le parcours de soins et la coopération entre professionnels. Les MG ruraux demandaient plus de professionnels : plus de praticiens, « plus de médecins et plus d'infirmières » et plus d'autres professions tels que « des diététiciens », « des psychologues » mais aussi « des infirmières de prévention ».

En ce qui concernait la rééducation, ils signalaient avoir besoin de « plus de centres de rééducation et de programmes », et ils émettaient le souhait de développer « la rééducation des patients à domicile ».

A propos de leur équipe, ils espéraient pouvoir mieux travailler ensemble avec une meilleure distribution des rôles avec les infirmières praticiennes, et une délégation des tâches au personnel paramédical ou aux travailleurs sociaux. « La gestion de la coordination des soins » devrait être améliorée selon les répondants, avec la participation d'un « gestionnaire de lits à l'échelle de la région pour savoir où envoyer des patients malades » si une hospitalisation s'avérait nécessaire. « Le développement d'unités de soins palliatifs non uniquement réservées aux patients atteints de cancers » ou de systèmes d'hospitalisations à domicile était également suggéré.

En troisième lieu, les participants mentionnaient des éléments de propositions autour des compétences des MG et la reconnaissance de leur investissement. « Moins de limites, plus de compétences » pourrait résumer ceci, avec comme domaines concernés les prescriptions (« supprimer la régulation des compétences des MG » pour les prescriptions de médicaments particuliers), ou alors leur propre formation initiale universitaire (« abaisser le niveau de spécialisation » pour en faciliter l'accès). Ils souhaitaient une meilleure reconnaissance notamment via la promotion de l'action des MG avec « des publicités présentant leur travail de tous les jours », mais aussi « une reconnaissance financière » plus particulièrement pour valoriser « le travail partagé » dans leur activité de coordination en soins primaires.

Pour ce qui est de la formation continue, certains médecins proposaient d'avoir « plus de cercles de qualité de MG », avec également des recommandations spécifiques et utiles notamment sur des thèmes tels que « comment gérer des patients avec des comorbidités ».

Patients et leurs proches

La principale suggestion faite par les praticiens à propos de leurs patients était d'améliorer leur éducation : éducation à la santé, et éducation thérapeutique avec des « sessions à long-terme ». Pour améliorer la communication avec les patients, les médecins proposaient d'utiliser plus de ressources telles que « des dépliants imprimés » et « d'enseigner ceci aux patients dans les écoles » ou « de former les étudiants sur les bonnes habitudes de vie ».

Pour ce qui est des problèmes d'adhésion, la plupart des MG suggéraient que les professionnels de santé viennent en aide aux patients, par « des listes en pharmacie », ou « une étude systématique des interactions médicamenteuses » par

les praticiens. Pour augmenter l'adhésion, les MG proposaient également que les aidants, les praticiens et les infirmières soient mieux formés. Les nouvelles technologies pourraient apporter d'après eux de réels bénéfices avec « des systèmes d'alertes par exemple avec une application mobile, des appels téléphoniques, des courriers électroniques » ou « des systèmes de décompte des pilules » (piluliers électroniques).

Au final, les MG ruraux appelaient à plus de soins centrés sur les patients. Ils soulignaient l'importance du rôle singulier du patient, sa propre responsabilité, et son autonomie « pour promouvoir les soins par le patient lui-même ». Dans ces soins orientés vers le patient, « un plus grand rôle aux associations de patients » était mis en avant par certains participants, alors que d'autres appelaient à des « réseaux de soins centrés sur le patient et non administratifs ». Ceci pourrait se faire au mieux « en coopération avec les infirmières, les spécialistes en soins palliatifs et les services communautaires ».

Maladies et polypathologie

Quelques suggestions étaient faites par les participants dans le domaine de la prévention, et pour améliorer la médecine préventive à un niveau national (« plus de tests de dépistages »).

Aussi, les praticiens faisaient ressortir la nécessité d'une « approche unifiée dans la gestion des maladies chroniques ». Cette gestion devrait réunir tous les composants de la pathologie chronique et de ses obstacles dans des « soins intégrés », de façon à avoir « un meilleur suivi des patients ».

Système de santé et son organisation

Un nombre conséquent de propositions a été identifié au sujet de situations locales ou nationales, plus particulièrement dans le registre des considérations financières. En ce qui concernait les revenus, la plupart des MG souhaitaient pouvoir bénéficier de plus d'argent, notamment pour les soins primaires, mais aussi « pour améliorer les services » de façon générale, ainsi que « pour la santé et une meilleure organisation » financière. Dans quelques pays en particulier, les médecins souhaitaient « une croissance économique », de façon à « réduire le chômage » et « augmenter l'éducation ». Un participant insistait, quant à lui, sur la nécessité de préserver « les traditions positives du système de santé » de son pays (Ukraine), dans le cas d'une réorganisation.

Sur le sujet de la place des MG dans le système de santé, ils émettaient la volonté de pouvoir bénéficier de meilleurs revenus (« une rémunération plus élevée pour le travail ») et de meilleures retraites. A ceci s'ajoutait aussi l'usage de nouveaux indicateurs d'évaluation de qualité plus simples, de façon à pouvoir apprécier un « suivi correct » des patients atteints de pathologies chroniques. Les praticiens souhaitaient une meilleure coopération avec les autorités sanitaires, avec notamment « plus de tables-rondes » (par exemple sur le sujet du chômage), et la promotion de systèmes tels que « les maisons médicales de santé ».

Au sujet des assurances santé, les participants au questionnaire proposaient un nombre plus important de compagnies d'assurances et « pas seulement qu'un seul système de fond de santé national ». Des dispositifs tels qu'une « carte personnelle pour contrôler le remboursement des médicaments » étaient demandés par un des répondants, alors que certains MG insistaient, quant à eux, sur la nécessité « d'un remboursement complet des traitements ». Ils souhaitaient également avoir la

possibilité « de discuter avec l'assurance maladie » de leurs problèmes rencontrés, et voulaient avoir moins de limites imposées par ces assurances dans leur exercice quotidien. En Finlande, les MG faisaient part de leurs attentes vis-à-vis d'un nouveau système de santé en cours d'instauration : « cela permettra peut-être d'améliorer les choses dans le futur ».

Aspects pratiques

Un petit nombre de participants faisait des suggestions à propos des difficultés d'ordre pratique. Sur le sujet des traitements, les MG mettaient en avant la notion de coût de ceux-ci, avec la nécessité d'avoir « des médicaments complexes de meilleur marché », et « plus de traitements à prix réduits ».

Pour améliorer leur connaissance du milieu local, ils se focalisaient sur la nécessité d'étudier la structure de la population locale (en termes d'âge, de lieu de vie, et « de zone géographique où les MG travaillent »). L'implantation des infrastructures en santé et hôpitaux était aussi à prendre en compte.

Atelier

20 participants (8 femmes, 12 hommes) étaient présents lors de l'atelier « pathologies chroniques » au congrès international de la WONCA Rural à Dubrovnik (divisés en 2 sous-groupes), représentant l'Australie, l'Autriche, la Canada, la France, l'Allemagne, l'Irlande, la Norvège, le Pakistan, la Roumanie, l'Espagne, la Suède, le Royaume-Uni (GB) et les Etats-Unis d'Amérique (USA). Les éléments récoltés au cours de cet atelier sont venus appuyer de manière convergente les données issues des questionnaires.

Groupe 1

Les sujets abordés par le premier groupe traitaient des soins communautaires, du travail en équipe multidisciplinaire autour du MG, et des notions de coûts. Tout d'abord, les participants relataient l'importance des services sociaux. Dans les pays développés les médecins décrivaient des familles plus petites donc une charge de travail des aidants naturels en augmentation. A l'opposé, les médecins des pays en voie de développement signalaient que la priorité était d'aider et développer d'abord les services de santé (Pakistan). De plus, les parcours de soins des patients étaient décrits comme différents dans les pays où coexistaient systèmes de santé public et privé, en matière de prescription et de suivi.

Un thème abordé par les participants était le rôle des infirmières communautaires qui pourraient donner non seulement des soins cliniques mais aussi « émotionnels » via une assistance psychologique (en étant formées pour). Dans certains pays (Autriche, Irlande, Norvège, Espagne), dans le domaine des soins communautaires, étaient décrites des organisations de volontaires, payées par l'Etat, mais avec un manque de coordination. Au Pakistan, les soins infirmiers étaient sous la responsabilité directe du médecin.

Les défis pour le futur étaient centrés autour de la question de la répartition des soins entre médecins et infirmières, mais portaient aussi sur la question de l'organisation de la sortie du patient de l'hôpital (quel serait le parfait timing ?) qui était décrite par les médecins présents comme étant de plus en plus précoce. Dans certains pays notamment en Espagne, des équipes spéciales hospitalières dédiées aux soins à domiciles pour les patients atteints de pathologies chroniques ont été mises en place. Aussi, entre autres moyens, ce dispositif s'appuyait sur un dossier médical partagé entre hôpital et MG ruraux pour les courriers de sortie et les prescriptions.

Groupe 2

Les questions abordées par le deuxième groupe étaient en lien avec la polymédication et autres problèmes liés aux médicaments, mais également avec les thèmes de l'isolement et de la fin de vie. Les participants se sont focalisés sur la manière de contrôler les traitements prescrits afin d'avoir toujours dans le dossier médical la dernière ordonnance du patient, notamment après une consultation chez un spécialiste ou à la sortie d'une hospitalisation. Un des participants faisait part aussi d'études menées en Allemagne sur le sujet de la polymédication, qui avaient comme objectif de définir des critères de priorisation concernant, non seulement les praticiens et les pharmaciens, mais aussi les patients. Certains soulignaient l'importance des recommandations pour le contrôle de la qualité et dans le cadre de la formation continue. Cependant, d'autres médecins présents considéraient que les MG devraient être prudents au sujet du suivi à la lettre des recommandations en particulier chez les patients fragiles. Le prix des médicaments était également mentionné comme un obstacle, en particulier pour les traitements des cancers ou de l'hépatite C (au Canada, et aux USA).

Dans le domaine de la prévention, les médecins du groupe 2 insistaient sur la nécessité du contrôle des addictions et du dépistage plus précoce des pathologies. Un des éléments clés pour l'avenir retenu par les participants, était la prise en main de leur propre santé par les patients, ainsi que leur responsabilisation. D'un autre côté, ils notaient également l'importance pour le MG d'une parfaite connaissance de la communauté d'exercice.

Les MG étaient aussi interrogés sur la gestion des fins de vie et des soins palliatifs en milieu rural. Des expériences positives étaient décrites notamment avec

les infirmières du réseau McMillan^{***} (UK), les forfaits de soins à domicile (Irlande), ou les allocations pour aidants en Australie ou au Canada. Une autre priorité évoquée par certains participants sur ce sujet était que le médecin devrait se sentir à l'aise pour discuter de la mort avec les patients, de façon à pouvoir définir leur projet de fin de vie afin d'apporter des soins appropriés à la maison ou en maison de retraite.

^{***} McMillan cancer support – <http://www.macmillan.org.uk>

Discussion

Avec la participation de praticiens issus de nombreux pays européens présentant des systèmes de santé variés, ce travail original a permis de réaliser un large aperçu des obstacles rencontrés par les médecins généralistes en milieu rural au sujet des pathologies chroniques.

Les praticiens ont principalement exprimé leurs difficultés, mais aussi ont fait part de leurs propositions pour un futur système de santé. Au delà de l'évocation d'idées générales ou de vœux pieux, certaines des suggestions pourraient être développées, entraînant des implications concrètes.

Cohérence externe et propositions

Les données récoltées dans ce travail étaient en accord avec la littérature. De précédentes études décrivaient les mêmes obstacles que ceux retrouvés dans le travail présent, parfois à des échelles plus locales, ou parfois à propos de maladies chroniques particulières(5)(12).

La non-compliance et le temps passé par le praticien avec le patient ont été décrits dans de précédentes études recherchant des indicateurs de détection des patients non compliant, notamment dans le domaine de l'hypertension artérielle (13). De plus, le nombre de pathologies chroniques et l'impact sur les activités de la vie de tous les jours pour les patients étaient aussi pris en compte dans cette étude centrée sur l'hypertension artérielle.

En règle générale, les MG soulignaient la nature complexe du management des pathologies chroniques et l'aspect consommateur de temps de ces soins(14). Un obstacle communément décrit en milieu rural, au sujet des patients atteints de pathologies chroniques, était la gestion du dossier médical, et le partage des

informations avec les autres praticiens, pharmaciens ou hôpitaux afin d'optimiser les soins centrés sur le patient.

Alors que certains praticiens ayant répondu au questionnaire présentaient une vision plutôt pessimiste à propos de leur charge de travail et du futur, Halvorsen et al. concluaient que les pathologies chroniques et leur prise en charge, ainsi que les soins de fin de vie étaient considérés comme faisant partie des activités professionnelles les plus porteuses de sens pour les MG norvégiens(15). Les éléments décrits comme moins intéressants que les autres étaient la rédaction de certificats, la gestion des problèmes psychosociaux et autres tâches administratives.

Les critères de satisfaction et d'insatisfaction pour les praticiens de premier recours travaillant en milieu rural ont été étudiés aux USA par Pathman et al., ainsi que la relation entre ces critères et le maintien de l'installation sur place(16). Parmi les réponses récoltées, certains participants avaient fait part d'obstacles identiques dans la relation avec les patients, des difficultés d'ordre bureaucratique (notamment sur les prescriptions médicamenteuses) et des problèmes de gestion du temps. Le maintien de l'installation était dépendant de la satisfaction des praticiens ruraux à propos du lien créé avec la communauté locale, mais aussi de la possibilité d'accomplir leurs projets professionnels. Ceci était également cohérent avec la thèse de Matthieu Sautel (17) à propos des moyens mis en place pour retenir ou inciter les MG à venir travailler en milieu rural, ainsi qu'avec celle de Anaïs Monin et Ingrid Millet (18) à propos des facteurs de satisfaction des MG ruraux français.

Néanmoins, il semblerait nécessaire de promouvoir la pratique de l'exercice rural en particulier dès les premières années d'études des professions médicales, paramédicales ou sociales(19). De nombreuses expériences positives ont été menées sur ce sujet et sont décrites notamment en Australie, aux USA ou en Allemagne(20)(21)(22)(23). Avec une meilleure compréhension de l'exercice en milieu rural et des spécificités de patients atteints de pathologies chroniques, les étudiants seraient probablement plus en mesure de choisir de travailler en milieu rural à l'issue de leur cursus.

La délégation des compétences concernant la gestion des pathologies chroniques vers d'autres professions de santé est également un des principaux challenges pour les soins primaires du futur, en particulier dans les zones rurales ou éloignées. Dans le même objectif que la mise en place d'infirmières praticiennes ou d'assistants médicaux, dans de plus en plus de pays, afin d'aider les MG dans leur prise en charge des patients(24)(25)(26)(27), de récentes réformes des systèmes de santé (par exemple en France) encouragent à développer plus de travail collaboratif entre les pharmaciens de ville et les médecins généralistes(28). Ceci serait bénéfique sur de nombreux points clés évoqués dans cette étude, notamment sur le sujet de la compliance, la polymédication ou sur le plan du travail collaboratif / gestion de l'équipe de soins(29). Des modèles de collaboration entre les professionnels de santé ont ainsi été étudiés dans l'objectif de définir le rôle exact et les compétences de chacun des acteurs, et ceci serait en mesure d'être mis en œuvre sur le terrain.

Comme illustré lors de l'atelier par les situations en Irlande ou au Royaume-Uni, mais également aux USA ou en Australie, l'assistance de travailleurs de santé

communautaires (ou issus de la communauté) était également une solution éprouvée pour faciliter l'exercice des praticiens de soins primaires.

Au regard des solutions décrites dans la littérature, l'apport des nouvelles technologies est largement promu comme moyen d'aide pour les praticiens et pour les patients atteints de pathologies chroniques en milieu rural(30)(31)(32). En outre, les moyens informatiques permettraient d'aider les MG dans leur gestion du dossier médical des patients ou de leurs prescriptions, en lien avec l'hôpital. Comme décrite par la plupart des participants à l'atelier dans cette étude, la mise en responsabilité du patient par lui-même est également une priorité et ces solutions technologiques pourraient y participer(33)(34).

Les patients atteints de pathologies chroniques représentent un réel défi médical dans les zones rurales. C'est pourquoi, de la même façon que la conférence annuelle espagnole réunissant tous les participants autour de la pathologie chronique^{†††}, il serait efficace de régulièrement faire l'état des lieux de la situation et de développer des actions communes.

Points forts et limites

Les sujets abordés dans les questionnaires (ainsi que lors de l'atelier) étaient récurrents et similaires ce qui permettrait de conclure à une bonne cohérence de cette étude. Pour ce qui est de l'acceptation interne, les éléments décrits par les participants ont semblé paraître sincères et réels.

^{†††} Congreso Nacional de Atención Sanitaria al Paciente Crónico
<http://vii.congresocronicos.org/>

Cette étude est le reflet des capacités de travailler sur un même projet entre plusieurs équipes de MG européens : que ce soit pour la construction du questionnaire et l'animation lors de l'atelier du congrès d'avril 2015 de la WONCA Rural avec les membres du groupe de travail « pathologies chroniques » d'EURIPA, ou encore que ce soit pour la collaboration avec l'équipe polonaise pour l'analyse des données quantitatives, mais également pour la coopération avec l'équipe turque pour l'analyse qualitative.

Cette analyse réalisée conjointement pour les données qualitatives est une des forces de cette étude, bien que les modèles usuels en ce qui concerne la méthode de triangulation des données n'aient pas été appliqués ici. Sans arriver à un parfait consensus, il existait néanmoins peu de divergences entre les analyses françaises et turques. L'analyse croisée a pu permettre de limiter les biais liés aux investigateurs notamment grâce aux différentes influences culturelles. Cependant, cet aspect transculturel pourrait être également considéré comme un possible obstacle dans l'analyse de ce travail du fait d'un partage des livres de codes réalisé de façon superficiel. Etant donné un laps de temps réduit, l'analyse conjointe pourrait donc être perfectible.

De nouveaux éléments sont apparus et d'autres ont été confirmés grâce à l'atelier ayant eu lieu lors du congrès WONCA Rural 2015, permettant ainsi de renforcer cette étude par un chevauchement de méthodes. La saturation des données a été obtenue pendant la deuxième phase d'acquisition des questionnaires. Après trois semaines de recueil des données, il n'y avait plus de nouveaux répondants et donc il

a été considéré que la source des données était épuisée et la collecte des données a été fermée.

Du fait d'une longueur probablement excessive du questionnaire d'enquête, un grand nombre de participants avaient renvoyé des questionnaires incomplets. Les questions spécifiques des sujets qualitatifs étant à la fin de ce questionnaire, il y a probablement eu une perte conséquente et progressive de données au fur et à mesure. Les réponses ont été également limitées par le manque de détails donnés par les participants lors des questions ouvertes.

De plus, il y a eu peu ou pas de réponses de la part de certains pays ce qui a pu apporter certaines limites à cette étude : il n'y a aucune réponse provenant de l'Albanie, de la Biélorussie, de la Bulgarie, du Danemark, de l'Estonie, de l'Islande, du Monténégro, des Pays-Bas, de la Serbie ou de la Slovaquie, et peu de questionnaires récoltés provenant de la Belgique, de la Croatie, de la Finlande, de la Grèce, de l'Irlande, de la Lituanie, du Luxembourg, de la Norvège, du Portugal, de la Suède, de la Suisse ou de l'Ukraine. Aussi, cette étude ne peut pas prétendre à être intégrale.

La grande diversité des origines des participants était aussi une limite du fait d'un niveau de compréhension variable des questionnaires : certains répondants n'ont ainsi pas compris des questions en anglais ou ont fait des contresens, et certains d'entre eux ont également répondu dans leur langue d'origine.

Egalement, les éléments relatés dans les questionnaires n'ont pas été contrôlés. Ceci pourrait être à l'origine d'un éventuel biais déclaratif.

Dans le même ordre d'idée, certaines particularités locales détaillées dans les réponses à propos de l'organisation des soins pour les MG, ou au sujet de systèmes de santé, n'étaient pas comparables d'un pays à un autre ce qui pourrait induire un éventuel biais d'interprétation, notamment par exemple au sujet de la manière de décompter le nombre de consultations par jour (personnes réellement vues ? appels téléphoniques décomptés ? résultats de biologies contrôlés ? etc.)

Du fait que l'atelier ait été introduit par une courte présentation issue des résultats des premiers questionnaires récoltés, il est possible que les investigateurs aient induits certaines réponses dans les groupes lors de la discussion. Toutefois, des données supplémentaires sont apparues à partir de cet atelier (notamment grâce à la participation d'autres zones géographiques telles que l'Australie, le Canada, les USA ou le Pakistan).

De même, le manque d'expérience de l'investigateur principal dans le domaine des analyses qualitatives doit être notifié, ce qui aurait pu éventuellement impacter la qualité du codage et l'analyse elle-même.

Comme autre limite de ce travail, seuls les praticiens étaient interrogés : il serait de ce fait pertinent de consulter également les patients, les autres professionnels de santé et les autorités sanitaires pour compléter ce tableau global.

Néanmoins, lors d'entretiens semi-structurés conduits auprès de patients vivant avec une insuffisance respiratoire chronique évoluée en milieu rural dans l'ouest du Canada, Goodridge et al. (12) ont retrouvé des résultats très proches dans les thèmes décrivant l'expérience de vivre en milieu rural avec une maladie chronique : gestion de la distance comme obstacle pour accéder aux soins, relation avec les médecins de

famille, importance du support de la communauté locale, manque d'éducation thérapeutique au niveau respiratoire et de support des pairs.

Dans une vision équivalente, d'autres études se sont focalisées sur le sujet de l'accessibilité aux soins de santé par les patients en milieu rural en Amérique du Nord, en Europe, en Australie et en Nouvelle-Zélande. Dans une méta-analyse, Brundisini et al.(35) ont rassemblé douze études qualitatives primaires à ce propos avec trois thèmes majeurs décrits (sur le plan géographique, au niveau de la disponibilité des professionnels de santé et autour de la culture rurale). Ainsi, ces données ont montré des intérêts et avis émis par les patients très proches de ce qu'ont décrit les praticiens dans ce travail présent.

Perspectives futures de travail

Une partie des données de ce questionnaire n'a pas été spécifiquement étudiée et discutée dans ce travail, notamment sur le sujet de l'évaluation des pratiques et de la prévention primaire. Dans le même ordre d'idées, des analyses croisées plus poussées entre données qualitatives et quantitatives pourraient être conduites dans un travail ultérieur tel que celui réalisé par Schäfer et al. qui ont récemment exploré cette voie avec l'étude QUALICOPC(10). Les auteurs ont ainsi recueilli les avis des patients et des praticiens sur le potentiel d'amélioration des soins primaires dans 34 pays de différentes conditions socio-économiques. Concernant les patients, l'exhaustivité des soins était une des caractéristiques des soins primaires présentant le plus grand potentiel d'amélioration, alors que les relations médecins/malade, en termes de communication, semblaient avoir un faible potentiel d'amélioration. Ils ont ainsi conclu que les pays aux soins primaires bénéficiant de meilleures conditions

économiques avaient moins de marge de manœuvre en termes d'amélioration pour les paramètres rentrant en jeu dans les soins centrés sur le patient.

Les particularités géographiques pourraient être également approfondies, comme par exemple entre pays de l'Ouest et de l'Est de l'Europe et selon leur système de santé.

Thèse soutenue par : Jean-Baptiste KERN

Titre : Problèmes soulevés par le suivi des pathologies chroniques en milieu rural et solutions proposées. Etude européenne.

Conclusion

Cette enquête a permis une collaboration scientifique originale entre médecins européens. Les praticiens travaillant en zone rurale ou éloignée ont pu exposer leurs problèmes à propos du suivi des patients atteints de pathologies chroniques, mais ont également pu faire part de propositions potentiellement porteuses pour améliorer ces difficultés. Les obstacles décrits portaient sur des thèmes liés aux patients et à leurs proches, aux pathologies elles-mêmes, au système de santé en place, aux praticiens concernés mais également sur des éléments d'ordre pratique.

Pour faire face à ces problématiques, les médecins généralistes ont déjà des solutions qu'ils ont expérimentées dans leur pratique courante, et leurs suggestions ont été recueillies lors de ce travail.

Certaines expériences locales positives décrites ici doivent être encouragées. Tout d'abord, il serait capital de sensibiliser les étudiants dès le début de leur cursus, qu'ils soient engagés dans des études médicales, paramédicales ou une carrière sociale, aux spécificités de l'activité rurale et aux particularités de la prise en charge des pathologies chroniques, notamment en favorisant des terrains de stages sur place. Ensuite, il serait nécessaire de définir et réévaluer régulièrement avec tous les acteurs concernés les objectifs concernant la prise en charge de ces patients au sein d'un congrès national, par exemple annuel, sur la thématique des pathologies chroniques en milieu rural. Un autre thème central à développer pour le futur est la gestion des intervenants en charge du patient et la délégation de tâches : rôle des infirmières

praticiennes, renforcement des dispositifs existant (par exemple comme réalisé par les infirmières au sein du réseau ASALEE en France(36)) notamment pour l'éducation thérapeutique, le dépistage et la gestion au long cours des patients atteints de pathologies chroniques.

Cependant, les médecins devront rester vigilants concernant certains points d'alertes, notamment en ce qui concerne les limitations établies par les autorités sanitaires sur leurs prescriptions (pour certaines classes thérapeutiques dans certaines maladies par exemple). Aussi, devront être regardées de près les questions autour de la compliance, du suivi médicamenteux et de la diminution de la polymédication (grâce à des critères de priorisation).

Ces points d'alertes et expériences positives pourront faire l'objet d'une prise de position d'EURIPA auprès des autorités de santé

Après cet aperçu global préliminaire, il serait intéressant d'interroger de la même sorte les patients et les autorités sanitaires pour recueillir leurs points de vue. De plus, une analyse croisée plus poussée des résultats obtenus prenant en compte l'origine géographique des participants, ou d'autres éléments quantitatifs pourrait permettre de compléter ultérieurement ce premier tableau.

VU ET PERMIS D'IMPRIMER.

Grenoble, le

Le Doyen :

J.P ROMANET

Le Président de la thèse :

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VU ET PERMIS D'IMPRIMER.

Grenoble, le 31/08/2015

Le Doyen :

J.P ROMANET



Le Président de la thèse :

PROFESSEUR J.P VUILLEZ



Rural practice and chronic morbidity, problems encountered and solutions.

A European investigation

KERN Jean-Baptiste

List of acronyms:

- ASALEE: French acronym for Health Action by Teams of Selfemployed Health Professionals
- EURIPA: European Rural and Isolated Practitioners Association
- EKG: electrocardiogram
- GPs: General Practitioners
- WONCA: World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

Keywords: Chronic Morbidity Problems Suggestions Rural Practitioners

Abstract

OBJECTIVES Purpose was to find out problems encountered by European practitioners in rural areas within their practice connected with care for chronic morbidity patients, and to collect their opinions, solutions already implemented and suggestions.

METHODOLOGY Qualitative descriptive study with prospective data collection was performed from February to July 2015 by questionnaire with additive results from April 2015 WONCA Rural meeting. Survey population was European rural general practitioners (GPs). Qualitative analysis was led jointly with the Faculty of Medicine of Eylul University Turkey.

RESULTS We collected 189 answers from 28 nationalities; age of respondents was: 27-76 years old (mean 48.7). Study group consisted of: 46% female respondents (IC95 39-53) and 54% male (IC95 47-61). Pathologies most frequently related were diabetes 82% (IC95 76-87), cardiovascular diseases 81% (IC95 75-86) and psychiatric disorders 71% (IC95 65-77). Main issues reported were: – Patients non-compliance, education issue, and reiterative consultations. –Diseases owing to problems of screening, a high prevalence and the association of several pathologies with dependence and disability. –Practitioners with mainly a lack of time for GPs and a sense of poor recognition of their involvement. –Health system due to bureaucracy, poverty / costs problems and the access to rehabilitation programs. –Practical difficulties linked with polymedication and distance problems.

CONCLUSION Beyond issues, some positive experiences have to be promoted and would be presented to health authorities in a position paper. However, GPs might keep vigilant on some critical points like limits on their competences.

Introduction / Background

In rural and remote areas patients are more and more aged with chronic morbidity and multi-morbidity(1)(2). Once past the challenge of a lack of a generally accepted international definition of rurality(3), differences were found in disability, morbidity and disease patterns according to living area, to the detriment of these regions(4)(5)(6). Moreover, socioeconomic status of specific populations in rural areas appears to impact adversely in situations with multiple pathologies(7).

Different health systems in Europe are providing care to patients with chronic morbidity. Questions about quality, costs and equity were subject to recent European studies about health care systems in 34 countries(8)(9) and the first results were presented to Health Authorities such as WHO (10).

Furthermore, General Practitioners (GPs) encountered problems in terms the support of chronic morbidity patients especially in rural and remote areas. This specific population represents a significant part of the practitioner's activity(11). To correct this, some GPs had already developed solutions in their practice.

It seems to be important to list these problems in order to have a clear view of the situation in Europe, and to be able at the end to establish a position paper available to health authorities.

Objectives

The aim of this questionnaire is to find out what problems are encountered by European practitioners in rural and remote areas in their practice in providing care to their patients with chronic morbidity. Also, we would like to collect their opinions, and

their solutions already implemented or suggestions in order to improve their practice with these patients.

Materials and Methods

This qualitative descriptive study with prospective data collection was conducted by a web questionnaire Lime Survey® (Free Open Source Software survey tool on the web) and with additional elements coming from a workshop about “chronic morbidity” during the WONCA Rural congress in Dubrovnik in April 2015.

The questionnaire was built by consensus between active members of the “chronic morbidity” working group of EURIPA using bibliographic data (questionnaire attached as annex).

Data collection was from February 2nd 2015 to March 20th 2015 and then from May 23th to July 6th 2015 to complete data in specific countries with earlier low or lack of answers.

The population is European rural general practitioners (GPs) approached by EURIPA “chronic morbidity” working group through the EURIPA mailing list (and a hot topic on EURIPA website), with the support of regional correspondents. Respondents were individually contacted by mail if further explanations or additional elements were necessary, especially with incomplete questionnaires.

The “chronic morbidity” workshop took place on April 16th 2015 during Dubrovnik WONCA Rural congress, and was recorded by dictaphone (2 subgroups, audio record 55min each). After a short presentation of the first results of questionnaires, each group was invited to debate and illustrate with elements based

on participants practice. Audio file transcription was performed cooperatively with the Clinical Investigation Centre of the University Hospital of Grenoble.

Only the specific data to answer the research questions has been used. Approach for the qualitative analysis was inspired by grounded theory. Qualitative data analysis was undertaken jointly with the Family Medicine Department Faculty of Medicine of the Eylul University, Izmir, in Turkey. Methodology for qualitative data needed at least two researchers working on their own, then comparing their analyses twice in order to do a consensus at the end (triangulation).

Quantitative analysis was conducted by the Family Medicine Department and the Department of Pharmaceutical Technology, of Wroclaw Medical University, in Poland. All statistical analyses were performed using the software Statistica StatSoft 12. Analysed variables were qualitative in nature (dichotomous), ordinal and compartmental.

As for number of patients per day, due to a poor number of subjects included in each group, the initial 12 groups were combined together to have 3 final subgroups (less than 26 consultations per day, 26 to 40, more than 40) to bring meaningful statistical analysis.

In order to determine relationship between ordinal variables, were used compared chi-square test. Depending on the size of dual tables, were also used chi-square test with Yates correction and Fisher's exact test, in determining relationship between variables in the tables used as multi-way analysis of correspondence. Level of significance when tested χ^2 was $\alpha = 0.05$.

For variables whose results were based on statistical scales, were determined interval descriptive statistics such as mean value, standard deviation, median and +/- 95% confidence interval. Normality of distributions for these variables were evaluated by three different statistical tests: Kolmogorov-Smirnov test, Lillefors test, and the Shapiro-Wilk at a confidence level $\alpha = 0.05$. Homogeneity of variance was assessed by tests: Levene and Brown- Forsyth at a fixed confidence level α level = 0.05. Statistical significance of differences between two mean values of the results with characteristics of variables was assessed – in the absence of significance tests for normality of distribution – parametric t-test for independent samples or parametric Cochran- Cox test for unequal variances. In case of variables that do not meet criterion of normal distribution of difference between two averages, was assessed non-parametric Mann-Whitney U test.

For comparisons of more than two means, were used – depending on the results of evaluation tests of normality and homogeneity of variance distributions – algorithms of parametric ANOVA or its equivalent nonparametric ANOVA Kruskal -Wallis test with median. In all tests, assessing statistical significance of differences between means, were adopted confidence level $\alpha = 0.05$. When afford significant differences between the average ANOVA – were performed several types of post-hoc comparisons: NIR Scheffe and Tukey RIR for unequal numbers.

Results

Description of the population

189 respondents, 102 men and 87 women were involved in the study, from 28 countries (table 1).

The average age of respondents was 48.7 years, the youngest person surveyed was 27 years old and the oldest 76 years. The variable age was not subject to the normal distribution at a given level of significance $\alpha = 0.05$ (table 2).

The average age of the surveyed women was approx. 45 years and men approx. 52. With the assumed significance level $\alpha = 0.05$, there is a statistically significant difference between the average age of men and women (table 3).

The average seniority of respondents in rural areas amounted to approx. 18.37 years. This variable was not subject to the normal distribution at a given level of significance $\alpha = 0.05$.

In the surveyed group, men worked in rural areas significantly longer than women. The average length of working for men was 20.73 years and for women 15.63 years.

33% of practitioners (n=62, IC95 27-40) saw fewer than 26 patients per day, while it was 26 to 40 patients for 34% of them (n=64, IC95 27-41) and more than 40 patients a day for 29% of the respondents (n=55, IC95 23-36).

There was not any significant statistical relationship between gender of the respondents and the number of patients admitted per day ($\chi^2 = 4.97$; $p = 0.08318$).

However, the analysis of correspondence showed that men take relatively more patients per day than women.

There was not a statistically significant correlation between the age of respondents and the number of patients admitted per day at the significance level $\alpha = 0.05$.

Median number of patients per day visited at home was 2 (min-max 1-45, lower-upper quartile 1-3). Median number of patients with chronic morbidity visiting the practice per day was 15 patients (min-max 0-200, lower-upper quartile 10-25).

The average length of a typical working day in rural areas amounted to approx. 8.73 hours. This variable was not subject to the normal distribution at a given level of significance $\alpha = 0.05$.

Table 1 Population

Respondents n=189

	n	%(IC95)	p-value(if available)		n	%(IC95)	p-value(if available)
Gender				Patients/day			
Male	102	54 (47-61)		less than 26	62	33 (27-40)	
Female	87	46 (39-53)		26 to 40	64	34 (27-41)	
<i>Total</i>	189	100		more than 40	55	29 (23-36)	
Age				Missing	8	4 (2-8)	
20-30	7	4 (2-7)		<i>Total</i>	189	100	
30-40	44	23 (18-30)					
40-50	48	25 (20-32)					
50-60	64	34 (24-40)					
60-70	24	13 (9-18)					
70-80	2	1 (0-4)					
<i>Total</i>	189	100	<i>p=0,000036 *</i>				

* Normalcy was evaluated with Shapiro-Wilk test at a given level of significance $\alpha = 0.05$

Table 2	Population 2		Respondents n=189	
	Mean (Median)	Std Dev	Lower-Upper quartiles (Min-Max)	p-value*
Age (years)	48.74 (49)	10.86	39-58 (27-76)	0.00036
Seniority in rural areas (years)	18.37 (18)	10.88	8.5-27 (1-45)	0.00003
Patients visited at home per day	2.66 (2)	4.08	1-3 (1-45)	<0.00001
Patients with chronic morbidity at the office per day	19.08 (15)	19.19	10-25 (0-200)	<0.00001
Patients with chronic morbidity visited per day	2.57 (1)	4.75	1-2 (0-50)	<0.00001
Children per day at the office	6.87 (5)	7.17	2-10 (0-40)	<0.00001
Work hours per day (hours)	8.74 (8)	2.29	7-10 (5-24**)	<0.00001

* Normalcy was evaluated with Shapiro-Wilk test at a given level of significance $\alpha = 0.05$

Table 3	Tests		Respondents n=189	
	Male Mean	Female Mean	Z-adjusted	p-value
Mann-Whitney U Test				
Age vs Gender	51.87	45.06	4.32	< 0.01
$\alpha = 0.05$				
Mann-Whitney U Test				
Seniority vs Gender	20.73	15.63	3.12	< 0.01
$\alpha = 0.05$				
Chi ²	Chi²	p-value		
Number of patients per day vs Gender	4.97	0.08		
ANOVA Kruskal-Wallis Test	Code	Valid N	Sum or Ranks	Mean Rank
more than 40	101	55	4516.000	82.1091
26 to 40	102	64	5606.500	87.6016
less than 26	103	62	6348.500	102.3952
Number of patients per day vs Age	H (2, N=181) = 4.7907		p-value	0.0911

Table 4 (part 1)

Activities *Respondents n=189*

GP management - income	n	%(IC95)	How do GP work	n	%(IC95)
Free settlement	53	28 (22-35)	Full time	156	83 (76-87)
Mandatory	10	5 (3-9)	Part time	20	11 (7-16)
Capitation	61	32 (26-39)	Other job*	20	11 (7-16)
Gate keeper	32	17 (12-23)	Hospital employment	1	1 (1-3)
National or regional health service	97	51 (41-58)	Academic involvement	37	20 (15-26)
Private insurances	18	10 (6-15)	Continuing education involvement	34	18 (13-24)
Other*	6	3 (1-7)			

*no further information

*as internist in a private practice; at the ministry of defence; 60% surgery 40% teacher in regional program; medical coordinator in an old people house; contract; CEO Physicians Network; occupational medicine; emergency care unit; NGO in a nearly urban area

Team in rural areas	n	%(IC95)	Risk factors	n	%(IC95)
Single	32	17 (12-23)	Pollution	33	17 (13-24)
Group of GPs	84	44 (38-52)	Poverty	90	48 (41-55)
Nurses	126	67 (60-73)	Drugs	47	25 (19-32)
Midwives	34	18 (13-24)	Alcohol	114	60 (53-67)
Physiotherapists	28	15 (10-21)	Professional risks*	36	19 (14-25)
Psychotherapists	11	6 (3-10)	Others**	22	12 (8-17)
Other health workers*	44	23 (18-30)			
Other specialists**	25	13 (9-19)			
Social workers	23	12 (8-18)			
Other***	10	5 (3-9)			

*community psychiatry; medical assistants; speech therapist; dentist; psychologist, dietician, osteopath

**Pharmacist; 3 other specialists; 1 paediatrician shared with other rural health centres

***nurses are in settlement nearby; secretary; manager, receptionist; one person; additional practice assistants

*farmers; seafarers, fishermen, lifeboat volunteers; asbestos; miners, carpenters, craftsmen; manual workers

**Tobacco; Nuclear plant under 30km; salt water; high elderly population, many live alone; agricultural labourer; unemployment;

Description of GPs activity (table 4)

Pathologies most frequently encountered were diabetes 82% (n= 155, IC95 76-87), cardiovascular diseases 81% (n=153, IC95 75-86) and psychiatric disorders 71% (n=135, IC95 65-77). GPs might deal with risk factors mainly as alcohol 60% (n=114, IC95 53-67) or poverty 48% (n=90, IC95 51-55).

As for sources of income, rural European physicians received compensation from National or Regional Health Services 51% (n=97, IC95 44-58), from systems of capitation 32% (n=61, IC95 22-35) and free settlement 28% (n=53, IC95 26-39). They mostly worked full-time 83% (n=156, IC95 76-87); some of them also had an academic involvement 20% (n=37, IC95 15-26). Just one respondent was working at the hospital (1% IC95 1-3).

In rural areas GPs worked with nurses 67% (n=126, IC95 60-73), with other GPs 44% (n=84, IC95 38-52) whereas 17% of them worked alone (n=32, IC95 12-23). The main activities of their practice were clinical such as paediatrics 59% (n=111, IC95 52-66) and out-of-hours organisation 33% (n=62, IC95 27-40), or instrumental like electrocardiogram 75% (n=142, IC95 68-81) or laboratory analyses 42% (n=79, IC95 35-49).

As for their electronic environment, most of them used professional software 76% (n=143, IC95 69-81), and had connection with laboratories 67% (n=126, IC95 60-73). Relations between GPs through electronic systems were revealed by 32% (n=60, IC95 26-39). Emerging technologies like use of medical phone-apps were mentioned by 36% (n=68, IC95 29-43).

Table 4 (part 2)

Activities in the practice	n	%(IC95)		n	%(IC95)
<u>Clinical activities</u>			<u>Instrumentations</u>		
Out-of-hours organisation	62	33 (27-40)	Electrocardiogram	142	75 (68-81)
Emergency unit	60	32 (26-39)	Respiratory investigation	74	39 (32-46)
Pregnancy / Gynaecology	57	30 (24-37)	Ultrasounds	38	20 (15-26)
Delivery	4	2 (1-5)	Laboratory	79	42 (35-49)
Behavioural therapy	23	12 (8-18)	X-ray	18	10 (6-15)
Paediatrics	111	59 (52-66)	Others*	45	24 (18-30)

*Family medicine; MF; occupational health care, a ward for 30 patients; Psychiatric ; Phlebotomy, warfarin clinic, skin surgery, community nursing unit, women's health, travel medicine, seafarers medicals, lifeboat medicals ; vaccinations ; mesotherapy ; oligotherapy ; palliative care ; manual medicine / chiropractic treatment ; infusion therapy ; surgery ; prevention of risk ; behaviour (alcohol); osteopathy ; minor surgery

Electronic environment	n	%(IC95)		n	%(IC95)
Professional software	143	76 (69-81)	Connection with other GPs	60	32 (26-39)
Connection with hospital	51	27 (21-34)	Connection with other specialists	53	28 (22-35)
Connection with laboratories	126	67 (60-73)	Medical smartphone apps	69	36 (29-43)
Connection with social and health services	25	13 (9-19)	Connection with help server for decision making	28	15 (10-21)
Connection with patients	38	20 (15-26)	Other*	12	7 (4-11)

*Connection with national informatics system; databanks; references/guidelines; palliative medicine; E-medicine is not fully involved in our country; don't have

Chronic diseases	n	%(IC95)		n	%(IC95)
Diabetes	155	82 (76-87)	Cancer	132	70 (63-76)
Cardiovascular diseases	153	81 (75-86)	Infectious diseases (e.g. HIV)	68	36 (29-43)
Rheumatism	132	70 (63-76)	Musculoskeletal disorders	132	70 (63-76)
COPD	131	69 (62-75)	Psychiatric disorders	135	71 (65-77)
Asthma	126	67 (60-73)	Other*	19	25 (19-32)
Aftermaths strokes	100	53 (46-60)			

*Obesity; Ocular disorders; Prostate hypertrophy; Dermatology; Ophthalmologic (glaucoma, cataract); Drugs and alcohol; Renal failure; Chronic pain and functional disorders; Neurological disorders, multiple sclerosis, Alzheimer diseases, Parkinson disease and other dementia; Cholesterol; Digestive disorders; Poly-pathology; Common infectious diseases; Contraception ; Thyroid disease (iodine deficiency); Respiratory system infections; I10.9; "Tired"; Allergy; I25.9; Injuries ; Autoimmune disorders; Sleep disorders like sleep apnoea syndrome; ORL diseases; Gastric problems (ulcers etc.); Anaemia; Administrative tasks; Behaviour risks; Poverty

Qualitative analysis:

Main problems

Five broad themes emerged from the analyses of the questionnaires as issues with chronic morbidity patients. First, problems related to the patients and their families; secondly issues linked with practitioners and care pathway; then those associated with the chronic diseases themselves and poly-pathology; then problems connected with the health system and its organisation; and finally those related to practical or geographical issues.

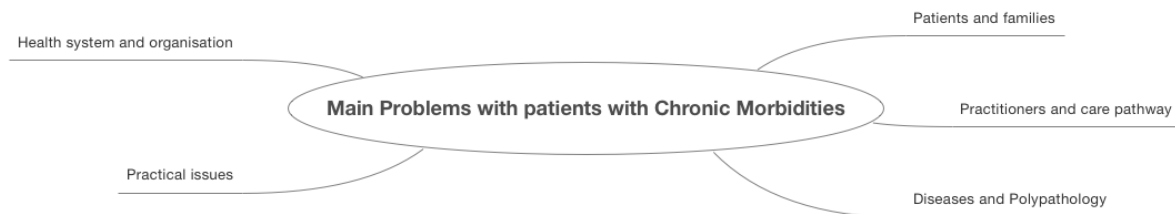


Figure 1 Main themes

Patients and families

In most of cases, the informants reported as a main issue non-compliance in treatments or for lifestyle changes (“adherence”, “observance” used as synonyms in the questionnaires). This view surfaced mainly in relation to the number of drugs to be taken everyday (“too many medicines to take”). In addition, European practitioners reported as explanations lack of time, “the increasing prices” of the medication but also due to the “elderly”, source of “confusion”. Moreover, patients with chronic morbidity “are not taking medication as prescribed”. GPs highlighted in the questionnaires “lack of motivation” (or “cooperation”) of their patients. “Not willing for treatments”. They concluded that there was a real communication issue with chronic patients.

The second obstacle was related to patients' education, especially about their medical or health education ("no responsibility", "low level of health education"). Furthermore, practitioners complained about patients' lack of competence : "Patients do not come to appointments regularly" or "patients are incompetent".

As for their living environment, GPs described patient lifestyles especially in terms of "bad habits" (listed as "obesity", "sedentary life", or "stress") and "difficulties [for the patients] to understand the relevance and effects of healthy living habits". Respondents presented also the loneliness issue (principally for the elderly population: "it is going to get worse with an ageing population"), and its impact in terms of care at home and for caregivers.

After all, a common view amongst questionnaires were the reasons for consultation: unfounded claims and reiterative consultations were sources of difficulties for practitioners. "Patients come too often with no reasons, just for a new prescription". At the opposite, some GPs regretted the "lack of regular check-ups".

Practitioners and care pathway

Time (and lack of time) was unanimously felt as a problem for practitioners: they put forward time management as an issue, due to "excessive duration of consultation time", an excessive number of patients ("too many patients per day", "too many disorders"). "Administrative tasks", "time fragmentation of care" were described as reasons for this management issue. It impacted also on their ability on continuing education. A number of GPs in rural areas linked to this subject of time a "lack of practitioners". As a pessimistic conclusion, one of the requested GPs said "the burn-out is always imminent".

About the care-pathway and multidisciplinary approach, rural physicians underlined difficulties in relationships with other specialists: “poor cooperation”, and “difficulties [in obtaining] specialist advice” (mainly due to “distance” or waiting times: “very long time is needed to reach a specialist”). As for coordination, GPs were in a bad way with respect to chronic morbidity because of “lack of team management” with all professionals in touch with the patient. They were concerned about the “monitoring between caregivers”, and had trouble “to [retain and] overview”. The patient’s role into her/his care pathway was not clear: “care is not focused on patients”. Moreover, accessibility due to the “rural location” was presented as a barrier.

Other questionnaires alluded to a lack of understanding of rural GPs’ work and the recognition of their involvement. They talked about the “absence of recognition of [their] job” or a “lack of means”, and the financial recognition linked to the time required for patients with chronic morbidities, “education time” or for their own pensions. Some felt that competences of GPs were limited due to “barriers [for some] drug prescriptions” while others considered that problems came from “trust by health authorities”.

Diseases and poly-pathology

One of the most perceptive issues related by the respondents was the association of multiple chronic morbidities. It induced problems with treatments (“complex medications”, “reduced possibilities of treatments”), a real social impact (“patients [...] cannot work and get a social handicap [...]”), exacerbated in the elderly population in particular when cognition difficulties occurred (“many are older patients without caregiver support and cognition difficulties, living alone or with their old partner too”).

The everyday-life impact was described by GPs as consequent with a “reduction of quality of life” for patients. This resulted in a high “handicap”, with “dependence” and “disability”. Chronic morbidities could impact in the patient’s “autonomy” with driving licence restrictions and some chronic diseases such as epilepsy and psychiatric treatments for example. In addition, “define and maintain a care plan” was reported as a challenge, moreover for end-of-life care.

The last main theme related by practitioners around diseases was about prevention. With a “high prevalence” for chronic morbidities, screening appeared as a key-point, and the principal issue with it was about the lack of interest for “first detection”. On the other side, GPs mentioned the importance of addictions, in particular about tobacco (and smoking consequences), alcohol (with “low quality alcohol drinking regularly”), drugs and other dependence problems. The problem of overweight was also highlighted by several European rural physicians.

Health system and organisation

A number of questions were identified about financial considerations. Poverty and social issues and lack of funding were the principals. As for poverty, it seemed to “decrease the chance for a good balance with chronic morbidities”. Bad social conditions with “low income” and “low pensions” implied that specific populations such as farmers, gipsies or pensioners (“who worked in the agriculture”) had difficulties in accessing the health care system. GPs regretted the “limited resources” for Medicine (“no money for Medicine”), and “budget cuts in healthcare expenditures”. This resulted for some practitioners in their country in difficulties “to purchase some specific equipment as ultrasound echography or EKG [...]”.

Furthermore, costs for healthcare were mentioned either as high (“high relative to income”, “high cost”) or as variables by country: there were de facto difficulties in “access to diagnostic” (for blood tests and exams) or for buying drugs (“high cost for the newest drug”). Reimbursement also was with a “variable part [remained] charged to the patient”, which posed the question to the rural practitioners of the “lack of medical insurance”.

In providing care (for patients with chronic morbidity) with-in their current health system, GPs identified issues about red tape and “bureaucratic barriers”, taking-up an “increasing” part of their work. One of the illustrations they mentioned about it was the “control of [their] prescriptions” for example specific allowance by the health insurance companies for antidiabetics. This implied difficulties in relations with the insurance companies, especially with privates. In general, practitioners concluded that there was a “[National] Health system failure” and “too few therapists in public care”.

When asked about access to rehabilitation programs, participants said that it was limited by the motivation of patients, the number of these programmes and of participants, their cost, and specific access for specific diseases. Centres of rehabilitation were sometimes far away from rural areas (with a “distance to the rehabilitation centre”), with long waiting lists. Besides, some informants commented that it was “not effective for the patient” and “not adapted to rural problems”. As for home care, there were difficulties in accessing it as well, for example “to have a physiotherapist at home”.

A common view amongst questionnaires was that “rural areas [were] left behind” in the health care system, and rural GPs felt that they had “to work much harder than in town”.

Practical issues

The first practical related theme concerned drugs and the medication. Practitioners raised the key problem of polymedication: there were “too many drugs”, with side effects and “drug interactions”. They encountered difficulties for the choice of “the right treatment”, due to recommendations, and to have “the efficient treatment”. Some prescriptions also had to be initiated by a specialist. Generic drugs, and “time dedicated to communication about [this]” emerged from the analysis as a problem. Moreover, there were other issues raised about drug cessation, due to “misunderstanding”, the cost or adverse reactions, but due to stock shortages as well.

The other main theme around practical issues concerned accessibility to rural and remote areas and distance. Physicians mentioned challenges to access the GP, or other specialist and investigations or health care services. Distance was the principal reason; there were a “long distance to the practitioner office” and for patients “a lack of services close-by”. Therefore, “technical specialities [were] often inaccessible”.

As for home care, “not many services [were] domiciliary”. With “no car and nor buses” in some part of these rural areas, transport (and lack of transport) was identified by GPs as a potential source of problems, especially for elderly. In conclusion, all of that increased “isolation of patients and practitioners” and “loneliness”.

In a few questionnaires infrastructures issues emerged like “power and internet outages”.

Successful action

Patients and families

As solutions already implemented in their practices, GPs gave examples of their resources to improve education. Diabetes was the chronic disease for which there were initiated a lot of therapeutic education sessions in most of the European countries, like “diabetes school”. To increase a patient’s autonomy, some countries established “back programme” for acute and chronic musculoskeletal diseases patients; some other programmes existed also for COPD. This was sometimes allowed through specific nurses like “ASALEE” in France, dedicated to chronic morbidities patients and screening.

To improve adherence to treatments, physicians mentioned the use of specific medication like “the 2 in 1 drugs”. Thanks to informatics and software, they were able to “calculate the best price for a prescription” and to see “patient’s electronic history”.

As for communication with patients, practitioners made use of “flyers for patients” or “wall announcements” to promote health care messages. But they also participated to “programmes for evaluation of the health of the population” to better understand their practice area.

Practitioners and care pathway

In order to have a better access to specialists, first of all GPs mentioned they tried to avoid the necessity of asking for this advice, especially for “problems [that could] be solved by a GP [...]”. When specialist advice was necessary, they employed “a fax connection [...] to declare a quick date”. GPs increased also their connection with specific specialities like psychiatry or rehabilitation centres.

About their healthcare network, practitioners indicated that they created specific networks dedicated to primary care, which were “focused-on [the medical support for] patients [at] home”. It needed good communication between all health and social professionals, especially for the elderly. In Spain, an annual multidisciplinary congress about chronic morbidity defined the objectives for the whole year (with doctors, nurses, social workers and patient’s associations). In France, there were MAIA named structures (Houses for Autonomy and Integration of Alzheimer patients) to take care of social problems of old aged patients with chronic diseases.

A number of solutions concerned team and office management: as much for their schedule with “appointment times”, and “15min per patient”, as for specific equipment like ultrasound (with “a separate contract with the National Health Insurance” in Romania), as for their team at the office. Indeed, they mentioned the experiences of “nurse practitioners” in the United-Kingdom, or building “houses medical centre” in France which associated many practitioners and health professionals.

When asked whether improved quality, respondents reported that “evidence-based medicine”, guidelines, quality circles and “error-documentation” groups helped them. There were specific examples with the Quality and Outcomes Framework (QOF) in the United-Kingdom and the German College of General Practitioners and Family Physicians (DEGAM) guidelines.

Diseases and poly-pathology

There were some comments about prevention and how to optimise the patient care pathway. About cancer patients, in Norway they just started a programme “to shorten and optimize complete examination of cancer suspects”.

GPs focused as well on screening for specific chronic morbidities like “diabetes and hypertension screening”, “cardiovascular risk factors”, “chronic respiratory diseases and tuberculosis” and “cancer”. Other mentioned “smoking cessation” programmes they were involved, or prevention of falls with eurhythmics like Jaques Dalcroze institute in Switzerland.

As for elderly patients, to improve their practice physicians made connections with specific administrative and medical networks that “significantly reduced the practitioner charge”.

Health system and organisation

About successful achievement in economic actions, respondents highlighted benefit effect of a “higher GDP” (in Romania) or other actions about medication prices.

Relationships with authorities with “round table sittings” were practiced in Sweden to speak about “sick-listing” and “unemployment”.

One of the challenges experimented with in some countries was about primary health care organisation with specific networks, “regional centres” and coordination “between hospitals and primary cares” (in Spain for example).

Practical issues

A common view amongst questionnaires was that technological solutions improved GPs practice. In some countries where they did blood exams at the office like in Germany, “the implementation of a centrifuge” reduced problems of accessibility to exams. In Turkey, a centralised informatics system called “AHBS” (for Family Medicine Information Systems) allowed for primary care physicians, nurses and midwives to report and record their actions with respect to vaccination or prescriptions.

To access health services, rural GPs in the United-Kingdom sent “nurses and assistants to see people at home”, meanwhile in Hungary “specialists are transported to the village [...] to screen population”. In Ireland, one respondent related local initiatives “with a bus to collect patients” especially for “elderly people living alone” to go to the “Day Centre for social and medical support”. A better access also included creation of an “address list of institutions” (social, psychiatric, associations etc.) like in Austria.

One discrete discourse emerged with a French practitioner that felt than rural practice allowed also better working conditions: “other health professionals are known”, with “the contribution of computers and technology” and due to “living comfort and quality if relationships with patients”.

Suggestions

No suggestions

A small number of European physicians signified that there were no solutions and had a pessimistic point of view: “our problems are just increasing”, or fatalism: “no one listens”.

Some practitioners mentioned also wishful thinking like “to have more money”, “changes in health system” or “another laws”, without more information.

Practitioners and care pathway

Most of the respondents made suggestions about their own practice especially about time management. To have more time they suggested first “to decrease bureaucracy” by “less red tape”, “less office work” or “less documentation”. Then, they

proposed “to reduce number of patients per day” and “to have more time with [each] patients”, in particular for chronic morbidity patients and for end-of-life support.

The second main part of their suggestion about their practice was about care pathways and cooperation with other professionals. Rural GPs asked for more professionals: practitioners, “more doctors and more nurses” and others like “nutritionists”, “psychologists” but also “preventive nurses”. As for rehabilitation, they needed “more rehabilitation centres and programmes”, and wanted to develop “rehabilitation at a patient’s home”.

About their team, they wished to work better together with a good distribution of roles with nurse practitioners and delegate tasks to paramedic staff or social workers. “Care coordination management” would be improved, in collaboration with someone as a “bed manager in the country to tell where to send an ill patient” if hospitalisation was necessary. “Support for non-cancer palliative units” or home care hospitalisation were requested as well.

Thirdly, the informants reported proposals about GPs skills and recognition of their involvement. “[Fewer] limits, more competences” could conclude that; about prescriptions (“cancel regulation of GP competences” about specific drug prescriptions), or their own academic training (“lowering of specialisation grade”). They wanted a better recognition to promote GPs action through “advertisement about [their] everyday work [...]”, but also “a financial recognition” especially for “shared working time” in their activity of coordination of primary cares. As for education, they hoped to have “more quality circles of GP”, specific and helpful guidelines in particular about “how to handle patients with comorbidities”.

Patients and families

The first main suggestion made by physicians about patients was to increase education: health education, and therapeutic education with “long-term sessions”. To improve communication, they suggested more resources like “printed leaflets” and “to educate patients in schools”, or “to educate students about healthy living”.

As for the compliance issue, most of the GPs proposed that health professionals helped patients with “pharmacy [lists]”, or a “systematic review drug interactions” by practitioners. To improve compliance, GPs wanted caregivers, practitioners and nurses also to be better trained. Emerging technologies could bring real benefits with “reminder systems [like] mobile app, phone calls, emails” or “pill counting-systems”.

Finally, rural GPs were calling for more patient-oriented care. They mentioned the importance of their own with their patients, and his/her autonomy “to promote the self-care of the patients”. For this patient-oriented care, “a stronger role for patient’s association” was put forward by some respondents while some others requested for “care networks focused on patient [...] and not [so] administrative”. This could be done “in cooperation with nurses, palliative care specialists and community services”.

Diseases and poly-pathology

There were some suggestions about prevention and how to improve preventive medicine on a national level (“more screening tests”).

Also practitioners mentioned the necessity of an “unified approach to the management of chronic diseases”. This management would have to combine all the components of chronic morbidity (and all its issues) into “integrated care”, in order to “better monitor patients with chronic illnesses”.

Health care system and organisation

A number of suggestions were identified about country and local conditions, especially for financial considerations. As for funding, most of the GPs asked for more money, in particular for primary care, but also “to improve services”, “for health and better management”. In some specific countries, they hoped for an “economic growth”, in order to “reduce unemployment” and to “increase education”. But one practitioner mentioned that “positive traditions of the system” (in Ukraine) might be preserved in case of health system reorganisation.

As for their own role into the health system, they suggested better payment (“higher payment for work”) and better pensions for GPs (“make larger pensions”). This would be possible with easier quality indicators as well, in order to appreciate “a correct follow-up” of chronic morbidity patients. Practitioners wished for more cooperation with authorities, with more “round table sittings” about unemployment for example, or to promote systems like “houses medical centre”.

About health insurance, they suggested to have more insurance companies and “not only one National Health Fund”. Systems with “personal card [...] to control refunding of drugs” were requested by one respondent; while some GPs reported the necessity of a “full reimbursement of medication”. They wanted also to have opportunity “to discuss with the health insurance” about their problems, and wanted to have fewer barriers in their exercise due to the insurance policies. In Finland, GPs were waiting for the opportunity of a new health system, soon: “[it] will perhaps help in the future”.

Practical difficulties

A small number of participants made suggestions about practical difficulties. As for medication, GPs reported elements about the cost of medication as the necessity to have “cheaper complex medication” and “more medication at reduced prices”.

To improve knowledge of local conditions, they focused on the make up of the population (age, where patients live, and “area where GPs work above”). The localisation of infrastructures and hospitals could also be improved.

Working-group

There were 20 participants (divided into 2 sub-groups) at the chronic morbidity workshop at Dubrovnik (8 women, 12 men) coming from Australia, Austria, Canada, France, Germany, Ireland, Norway, Pakistan, Romania, Spain, Sweden, the United-Kingdom (UK) and the United-States-of-America (USA). Elements reported from the working-group were convergent with questionnaires data.

Group 1

Group1 talked about community care, multidisciplinary team around the GP and costs. First of all, the informants reported the importance of social services. In developed countries, families were smaller so burden on care givers increased; they mentioned also the increasing ageing population in rural area. At the opposite, the developing world needed first of all help and support to develop its health services (Pakistan). Moreover, patient care was different in countries where there coexisted private and public systems in term of prescriptions or monitoring.

A common view amongst interviewees was the role of community nurses which could give clinical care but also could give emotional care (if they were trained for this). In some countries (Austria, Ireland, Norway and Spain), there were state funded voluntary organisations but with a potential lack of coordination. Whereas in Pakistan, nurse care was dictated by the doctor.

Challenges for the future were defined around the question of who should provide the care between doctors or nurses, but also about the best time for hospital discharge (earlier and earlier). In some countries like Spain, there were special teams from the hospital dedicated to home care for patients with chronic morbidity. They shared clinical medical and prescriptions records with rural GPs.

Group 2

Group 2 was initially questioned about polymedication and drugs issues, but themes of loneliness and end-of-life were also discussed. Participants focused on the control of medication to have the last prescription in medical records on the computer after a specialist consultation or when a patient was discharged from hospital. Some studies were conducted in Germany about polypharmacy in order to define criteria for prioritisation that applied to not only practitioners and pharmacists but also patients. Some felt that guidelines were important for quality control and continuing education, while others considered that GPs should be aware about guidelines especially with patients in frail. Price of medication was also mentioned as an issue, especially for cancer drugs or hepatitis C treatment (Canada, USA).

Preventive challenges as a control of addictions or necessity to screen illnesses at an early stage were also reported. One of the major elements for the future for a majority of the informants was the necessity for patients to take their own responsibility. On the other side, GPs might have perfect knowledge of the community.

GPs were asked about end-of-life and palliative care in rural areas. Some positive systems were reported like McMillan nurses in UK, home care packages in Ireland or carers allowance in Australia or in Canada. To be comfortable discussing death was one of the priorities held by some participants, in order to define an end-of-life project with appropriate care at home or at the hospice.

Discussion

With the participation of many different European countries with many different health systems, this original work has shown a broad overview of issues encountered by rural practitioners about chronic morbidity.

Practitioners mainly expressed their difficulties, but also their proposals for future solutions. Beyond general ideas or wishful thinking to a large extent, some of these suggestions could be developed further with practical implementation.

External consistency and propositions

Data raised in this present work were consistent with the literature. Previous studies about chronic morbidity mentioned thematic issues or local conditions, sometimes about specific diseases(5)(12).

Noncompliance and time spent by the physician with the patients were described in a previous study to seek indicators to be able to detect noncompliant patients in particular about hypertension (13). Furthermore, the number of chronic illnesses and the impact on everyday activities for patients were also included.

Generally, were underlined for GPs the complex nature of chronic-disease management and time-consuming aspects of care(14). A common major issue for rural patients with chronic morbidity was management of their medical record, and shared information with other practitioners, pharmacists or hospital in order to have better focused patient care.

Whereas some practitioners presented a pessimistic view about workload and the future, Halvorsen PA et al. considered that chronic somatic diseases and terminal care were part of the most meaningful activities for Norwegian GPs (15). Items with low

priority among others were certificates, psychosocial problems or other bureaucratic tasks.

Criteria of satisfaction and dissatisfaction for primary care physicians working in rural areas across the USA and its source of relationship to retention were studied by Pathman and al. (16). Some respondents mentioned comparable issues here in relationships with patients or difficulties like bureaucratic interference (including drugs prescriptions) or time management. It was also consistent with Sautel's thesis about means applied to retain or encourage GPs to work in rural environment (17) or Monin and Millet thesis about satisfaction factors of rural GPs in France(18).

Nonetheless, it would appear to be necessary to promote rural practice in particular among medical, paramedical and social studies(19). Some positive experiences were related in Australia, USA or Germany(20)(21)(22)(23) about it. With a better understanding of rural exercise and chronic morbidities patients, these students would probably be more likely to practice in those areas in the future.

Delegation of competences about management of chronic morbidities to other health professionals is one of the primary challenge for the future especially in rural and remote areas. As for the implementation of nurse practitioners or physician assistants in more and more countries to help GPs in patient support (24)(25)(26)(27), recent healthcare reform encourages (e.g. in France) community pharmacists and general practitioners to develop collaborative care(28). This should be beneficial in many elements raised as issues in the study like compliance, polypharmacy, or collaborative work / team management(29). Models of collaboration between health

professionals have been studied in order to define each provider role and skills, and it should be translated into actions in the field.

As illustrated in the workshop by situation in Ireland or UK but also in the USA or in Australia, the help of community health workers was also a solution to extend the reach of primary care physicians.

With regard to the solutions described in the literature, the contribution of new technologies is widely promoted to help practitioners and chronic morbidity patients in rural area (30)(31)(32). Additionally, informatics means could help GPs into the management of patient medical record or medication in connection with the hospital. As described by most of the workshop participants, patient's own responsibility is also a priority and these technological solutions could be involved in (33)(34).

Patients with chronic morbidities represent a real challenge in rural areas. Therefore, like the Spanish annual meeting of all stakeholders involved with chronic morbidity, it would be efficient to regularly take stock of the situation and to develop adapted common actions.

Strengths and limits

Topics mentioned in questionnaires (and the workshop too) were recurrent and similar which could lead to the conclusion of a good internal consistency in this study. As for internal acceptance, items reported by participants seemed to be sincere and real.

This work reflects the ability to work together between several European GPs teams: questionnaire construction and facilitation of the workshop at the WONCA Rural congress with the EURIPA chronic morbidity working group, collaboration with a Polish team for quantitative data analysis, and cooperation with a Turkish team for qualitative analysis.

The joint analyses with Turkey for qualitative data is one of the strengths of this work, although the usual model of triangulation has not been implemented. Without reaching consensus, there were still limited discrepancies between French and Turkish analysis. Themes found were very similar. Cross analysis allowed us to limit bias due to investigators like an eventual cultural influence. However, transculturality could be a possible issue in the analysis of the present work due to a slight code-books sharing. Given that there was not an adequate time, joint analysis could be improved on.

Some new elements came from the WONCA Rural congress workshop, which was a real strength by overlapping methods. Data saturation was achieved during the second part of questionnaire collection. After three weeks, there was no new respondent so it was considered this source of data was exhausted, and data collection was closed.

But due to a probable excessive length of the survey, many participants sent incomplete questionnaire. Qualitative specific questions were at the end of the survey, so there was probably a consequent and progressive loss of data. Answers were also limited by open-questions where participants did not give enough details.

Moreover, there were lack of or poor answers from specific countries that could bring some limits to this study: there were no answers from Albania, Belarus, Bulgaria, Denmark, Estonia, Iceland, Montenegro, the Netherlands, Serbia and Slovakia; and poor questionnaires from Belgium, Croatia, Finland, Greece, Ireland, Lithuania, Luxembourg, Norway, Portugal, Sweden, Switzerland and Ukraine. Therefore, completeness was not attained.

The great diversity of origin of respondents was also a limit due to a variable level of understanding of the questionnaire: some respondents did not understand some questions in English or mistook them, and some of them replied also in their own language.

Furthermore, elements reported into the questionnaire were not controlled. This could have induced a potential declarative bias.

In the same way, some local specificity reported in the answers about care organisation for GPs or about healthcare systems were not comparable and could lead to interpretative bias, for example about how to count consultations per day.

While the working group were introduced by the first analysis of the questionnaire, the influence of the investigator could have induced answers of the groups. Nevertheless, this workshop led to the emergence of new elements (with participants of other geographical area like Australia, Canada, USA or Pakistan).

Also, the lack of experience in qualitative analysis by the investigator might be mentioned, that could impact on coding quality and the analysis.

As for other limits of the current work, only practitioners were asked for their opinions, so it should be also relevant to consult patients, other professionals and health authorities to complete this global picture.

Nevertheless, in semi-structured interviews conducted with patients living with advanced chronic respiratory illness in a rural area of Western Canada, Goodridge et al. (12) recovered very similar themes that characterised the experiences of living in a rural setting with respiratory chronic disease, like distance as a barrier to accessing health care, relationships with family practice physicians, supportive local community and lack of respiratory education and peer support.

In the same way, some other studies focused on the topic of access to health care for rural patients with chronic disease in North America, Europe, Australia and New-Zealand. In a meta-analysis, Brundisini et al. (35) mentioned 12 primary qualitative studies about it with three major themes (geography, availability of health care professionals and rural culture). Thus, these reports have shown patients' very close concerns with those of healthcare practitioners in this present work.

Future prospects

Part of data from the questionnaire returns were not specifically discussed in this work in relation to primary prevention or evaluation. In the same way, further crossed-analysis between qualitative and quantitative data could be investigated in a future work like Schäfer and al. who recently explored this way with QUALICOPC study(10). They investigated patients' and practitioners' perceptions of improvement potential in primary care in 34 countries with different economic level conditions. The results for patients' comprehensiveness of care was one of the features of primary care with major improvement potential whereas doctor-patient communication had low

improvement potential. They concluded that countries with better economic conditions for primary care had less potential for improvement of all features of person-focused care.

Geographical particularities could be explored as well, for example between Western and Eastern countries.

Conclusion

In this original European collaboration, rural and remote area GPs shared their difficulties about chronic morbidity patients, but they mentioned also some interesting proposals to improve these issues. So practitioners must be aware of the difficulties of patients and their families, the diseases, the health system, their own practice as well as practical aspects.

Beyond these issues, GPs already have solutions that they have experimented with in their current practice, and they made suggestions.

Some positive experiences need to be promoted. First of all, it is necessary to have a better knowledge of chronic diseases and rural areas in early studies for medical, paramedical or social caring professions, including local internships.

Defining the objectives with all stakeholders through annual or regular meeting around chronic morbidity in rural and remote areas is another concept worth promoting.

Another major key-theme to be developed for the future is team management and work delegation: role of nurse practitioners, and some current solutions (like ASALEE nurses in France(36)) for therapeutic education, screening and management of patients with chronic morbidities.

However, practitioners need to keep vigilant on alert points like limits imposed by health authorities on their competences (for some drugs prescriptions for example). Furthermore, compliance issues, medication monitoring and how to handle with polymedication (criteria of prioritisation) have also to be supervised.

These alert points and positive experiences would be subject to a position paper to the health authorities.

After this first global work, it would be interesting to ask European patients and health authorities for their points-of-view.

Moreover, an acute cross-analysis by geographical origin or with quantitative data could be done to complete this first picture.

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Annexes

Questionnaire

Tableau et carte des participants

Mapping des résultats, aperçu global

Verbatims de l'atelier du congrès WONCA Rural 2015

Version électronique exclusive :

- Tableau brut de données
- Tableau de code : problèmes, solutions, suggestions (et classement des réponses par pays)
- Double analyse (équipe turque)
- Mapping complet

Afin de faciliter la lecture des annexes et l'exploitation ultérieure des données, les fichiers (tableaux, mapping, PDF du questionnaire) ont été fournis en version électronique sur clé USB aux membres du jury de thèse et seront partagées en ligne sur la plateforme DUMAS CNRS^{##}
(sous réserve de validation du contrat de diffusion électronique)

^{##} <http://dumas.ccsd.cnrs.fr>

ICT Health Grenoble - Chronic morbidity in rural setting

Chronic morbidity in rural setting

The aim of this questionnaire is to find out what problems are encountered by practitioners in their practice in providing care to their patients with chronic morbidity in Europe.

Dear colleagues,

In rural areas patient are more and more aged (compared to urban areas) with chronic morbidity and multi-morbidity. We would like to know your problems , your opinions and what type of solutions you realize or suggest or solutions already implemented.

This questionnaire will take about 15 minutes to answer, if you wish your responses could be anonymized.

The first results of this survey will be the starter at a workshop on Dubrovnik meeting. (<http://woncarural2015.com/>)

All your responses are very important, to have a clear view of the situation in each european country, to be able at the end to establish a position paper available to health authorities.

If a question is unclear for you or non relevant for the health system within you work do not hesitate to add comments.

the "chronic morbidity" work team of EURIPA.

There are 30 questions in this survey

Who are you?

1 [Q1]How old are you? *

Please write your answer here:

2 [Q2]Gender *

Please choose **only one** of the following:

Female

Male

3 [Q3]

How long have you practised in rural areas ?

Please write your answer here:

in years, (if less than one, select 1)

4 [Q18] In which country, and region, county or area do you practice?

Please write your answer here:

5 [Q16] How many patients do you see on average per day, in your practice?

Please choose **only one** of the following:

- less than 15
- 16 to 20
- 21 to 25
- 26 to 30
- 31 to 35
- 36 to 40
- 41 to 45
- 46 to 50
- 51 to 55
- 56 to 60
- more than 60

in average in a year. It is an average taking into account seasonal variations and other factors.

6 [Q4] how many patients per working day do you visit at home?

Please write your answer here:

7 [Q5]how many patients with chronic morbidity (including children if relevant) per day visit your practice ?

Please write your answer here:

on average in your opinion

8 [Q17]how many patients with chronic morbidity per working day did you visit at home?

Please write your answer here:

9 [Q6]How many children per day visit your practice?

Please write your answer here:

(number)

10 [Q7]

How many patients a day visit your office for preventive reasons and/or screening?

Please write your answer here:

number approximatively

11 [Q8]What is the way of your GP management, how is your practice funded ?

Please choose all that apply:

- free settlement
- mandatory
- capitation
- gate keeper
- National or regional health service
- Private insurances
- other (please discribe at the end of the questionnaire)

12 [Q9]People I work with

Please choose all that apply and provide a comment:

- single handed
- in a group of GPs
- with nurses
- with midwives
- with physiotherapists
- with psychotherapists
- with other health workers
- with others specialists
- with social workers
- other

At the end of the questionnaire you can describe your practice more acurately.

13 [Q10] how long do you work a typical day? (in hours)

Please write your answer here:

14 [Q11]how do you work

Please choose all that apply and provide a comment:

- Full time ?
- Part time?
- Other job ?
- Hospital employment ?
- Academic involvement?
- continuing education
involment?

15 [Q12]Which activities do you do in your practice

Please choose all that apply and provide a comment:

- Out of Hours organization
- Emergency unit
- Electrocardiogram
- Respiratory investigation
- Ultrasounds
- pregnancy gynecology
- delivery
- laboratory
- Xray
- Behavioural therapy
- Pediatrics
- others

16 [Q13]Electronic environment.

Please choose all that apply and provide a comment:

- patients data recorded on a professional software
- connection with hospital
- connection with laboratories
- connection with social services, health services
- connection with patients
- connection with others GPs
- connection with others specialists
- connection with nurses, midwives
- do you use medical apps
- Connection with help server for decision making
- other

17 [Q15]Have you any environmental risk factors close to your GP practice?

Please choose all that apply and provide a comment:

- pollution
- poverty
- drugs
- alcohol
- professional risks (eg: miners, fishermen)
- others

18 [Q14]Your mail adress:

Please write your answer here:

Chronic morbidity

19 [2Q1]Number 1 to 10 (1 is the more prevalent after 2 etc.) the most common chronic diseases you meet in your population (name 10 diseases in the order of prevalence)

Please choose all that apply and provide a comment:

<input type="checkbox"/> Diabetes	
<input type="checkbox"/> Cardio vascular diseases	
<input type="checkbox"/> Rhumatisms	
<input type="checkbox"/> COPD	
<input type="checkbox"/> Asthma	
<input type="checkbox"/> Aftermaths Stroke's	
<input type="checkbox"/> cancer	
<input type="checkbox"/> infectious diseases (HIV)	
<input type="checkbox"/> Musculoskeletal disorders	
<input type="checkbox"/> psychiatrics disorders	
<input type="checkbox"/> other	
<input type="checkbox"/> other	
<input type="checkbox"/> other	
<input type="checkbox"/> other	

eg: diabetes, CV diseases, rheumatology, COPD, asthma, cancer, infectious diseases (HIV), other?

If you want you can answer with International Classification of Diseases (ICD-10) codes

or with International Classification in Primary Care (ICPC 2) codes.

20 [2Q2]:Are there any prevention programs for patients with chronic morbidity

Please write your answer here:

eg: cessation campaign smoking for patient with COPD or training to walk for patients with diabetes.

21 [2Q3]

Are there any quality indicators in your contracts with a (national) health insurance?

Please write your answer here:

22 [2Q4] Are there any evaluation tools or programs for assessment in primary cares ?

Please write your answer here:

eg: peer review, quality circles.

23 [2Q5]

Are there "pay for performance" (P4P) programs?

Please write your answer here:

Problems

24 [3Q1]

What are the main problems with patients with chronic morbidities?

Please write your answer here:

25 [3Q2]cost of medications and drugs

Please write your answer here:

eg:costs remain charged to the patient? over the counter ?

26 [3Q3]Cost of rehabilitation programs

Please write your answer here:

eg: training program after stroke, part remain charged to the patient?

27 [3Q4]Are there any problems not listed above, can you describe them ?

Please write your answer here:

Which solutions?

28 [4Q1]Do you know a successful action implemented in your practice to correct a problem

Please write your answer here:

eg:physiotherapy reimbursed, or access to specialist easier.

29 [4Q2]Have you suggestions which could be , in your opinion, able to decrease your problems?

Please write your answer here:

Have you something to add ?

have you any documents, texts, bylaws, links or websites (from authorities, NGO ...) which can contribute to a better understanding on the topic in your country or area?

30 [5Q1]

Have you something to add (even if you thought that it's not in the topic)

Please write your answer here:

ICT Health Grenoble - Chronic morbidity in rural setting

Thank you for your participation, the results will be in EURIPA website.
If you left your mail address you will be notified personally.

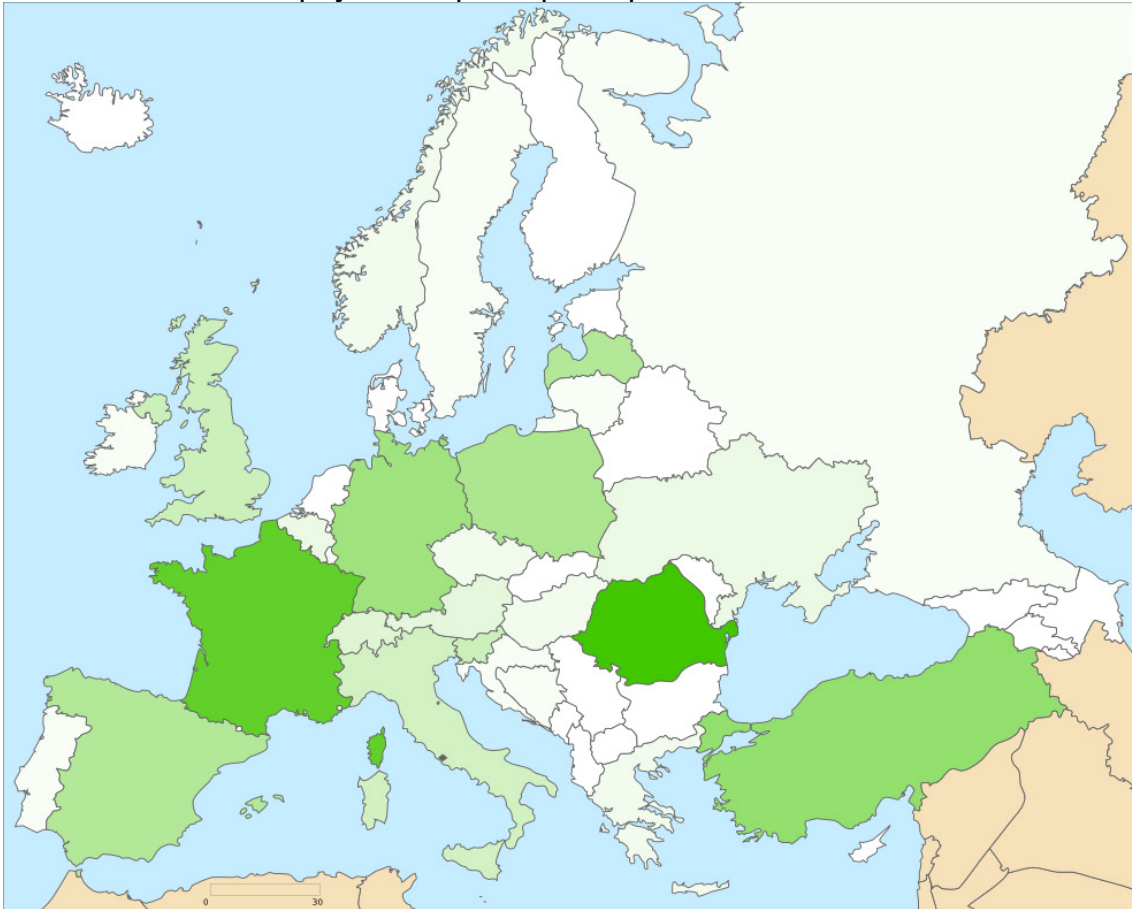
We will appreciate if you can sent the link of this survey to another rural GP.

01.01.1970 – 01:00

Submit your survey.
Thank you for completing this survey.

Carte des participants à l'étude

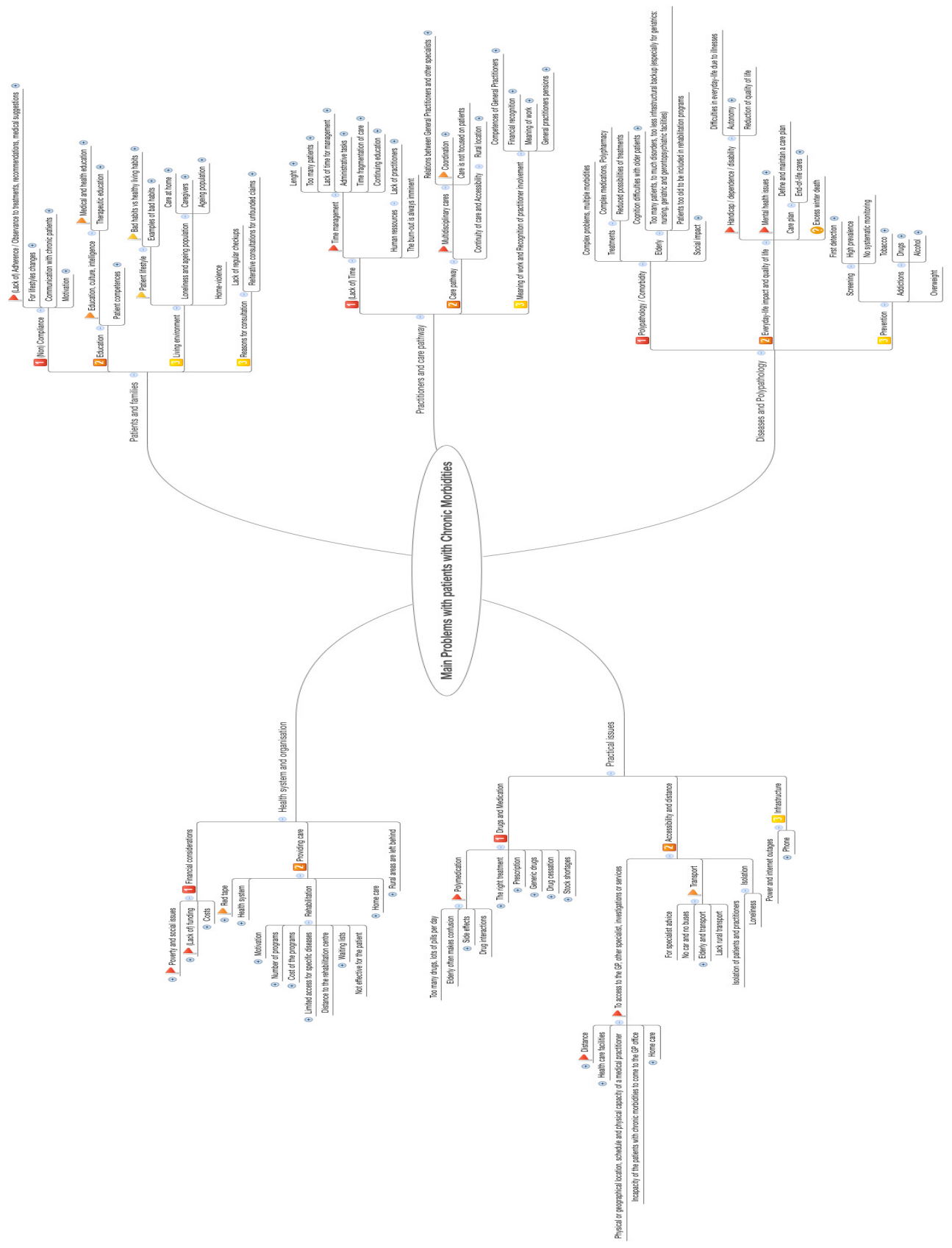
Tableau des pays : 189 participants provenant de 28 nationalités



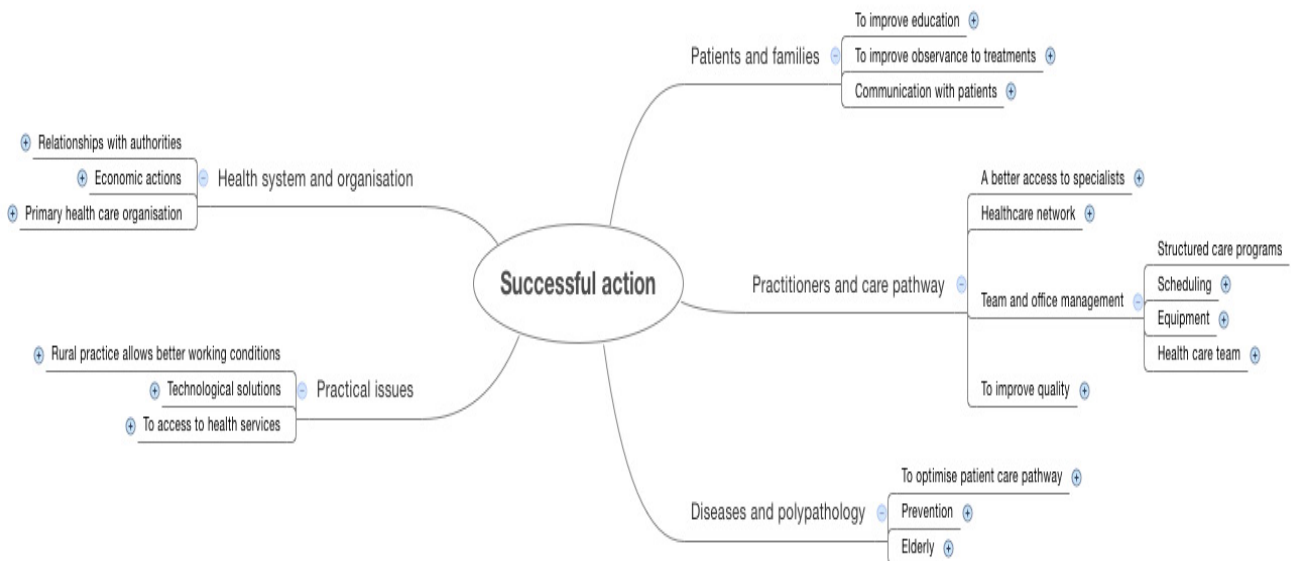
Pays	Nbre de participants	Pays	Nbre de participants
Autriche	4	Lituanie	1
Belgique	3	Luxembourg	1
Bosnie-Herzégovine	1	Norvège	2
Canada	1	Pologne	13
Croatie	1	Portugal	1
République Tchèque	2	Roumanie	30
Finlande	3	Russie	1
France	25	Slovénie	8
Allemagne	15	Espagne	12
Grèce	2	Suède	1
Hongrie	2	Suisse	5
Irlande	1	Turquie	17
Italie	7	Ukraine	3
Lettonie	12	Royaume-Uni	8
Manquant	7	/	/
		Total	189,00

Mapping

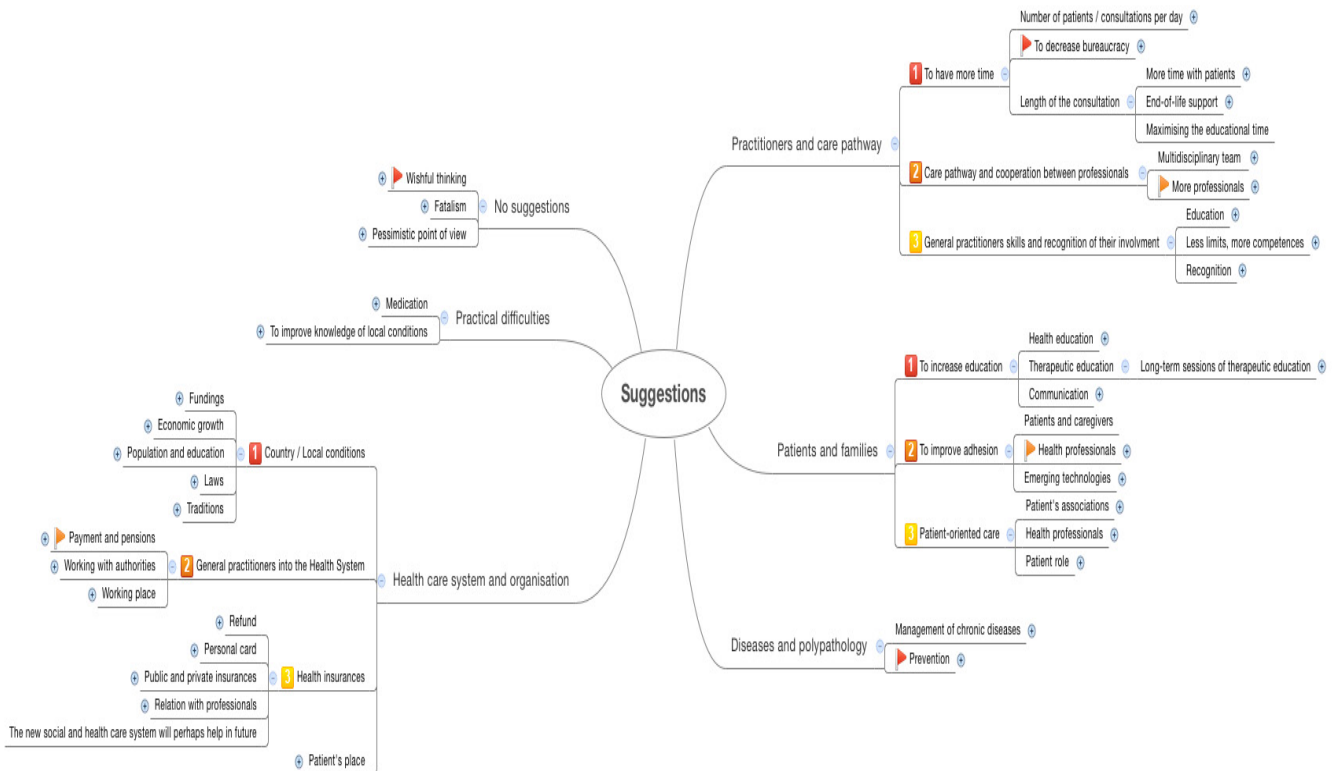
Main problems



Successful action



Suggestions



(cf. version informatique pour une meilleure lisibilité des arborescences)

Working in rural areas...



Verbatims atelier

Group 1

Chronic morbidity in rural areas: community care. Around the care pathway

NOT ALL THE PARTICIPANTS INTRODUCED THEMSELVES AT THE START OF THE DISCUSSION GROUP SO IT IS DIFFICULT TO IDENTIFY WHO IS SPEAKING, EXCEPT THAT IT IS A MAN OR A WOMAN

NOISE

- Man(?): I also take part in public health, so, I'm a district medical officer

- Woman1 (Austria): Sorry I 'm getting my instructions, I'm *** from Austria but actually I'm working in a city with fifty thousand inhabitants, so my work is not difficult for rural medicine.

- Group Leader (UK): But it will be interesting when we discuss the issues; you all have different ways of working that it might be interesting for us to hear about.

- Woman2 (Sweden): My name is ***, I'm coming from Sweden; the middle of Sweden. I've been in place for one year. It's a temporary position

- Group Leader: Welcome, I'm ***. I'm not actually a GP so I will do my best to capture what you say. I've just been given another recorder

We were originally going to have 3 groups but we're only got 2 and there are different areas: a care pathway and how you relate to the health system and we'd like to explore with you what you think your problems are and where things are really working well for you. So, are you all in multidisciplinary teams, in your practices?

- Man1 (Ireland): No we're not really in multidisciplinary teams, well, when you say we work in isolation; that's not true either, we've got a practice nurse, and we've got

support services but we don't work directly with them, we refer to them, but haven't any direct contact with them

XXX (noise)

- GL: So do you have community nurses? People who ...

- Man1 (Ireland): Yes, they're not necessarily part of our team though, we don't see them on a daily basis or have any designated interactions with them. So they're there and we can call them. They're not really part of the team.

- GL: so would you have ..., if you've got a patient who's got a number of different conditions, would you have a sort of team meeting, and call other people in to discuss.

- Man1 (Ireland): No. There has been an effort to set up primary care teams in Ireland, but it hasn't really taken off. They're set up sporadically in different areas, but they're not really widespread. So we are kind of left with the coordination.

- GL: So GPs are very much the coordinators and the gatekeepers. Is that the same in other countries?

- Man2 (Norway): Actually in Norway we have er..., I think it might be the same in Sweden, because I've been working there as well. But in my practice we have 3 GPs and we have weekly meetings with district nurses and a sort of psychiatric team which is located in the same house (building) as us. But home nurses taking care of the elderly people they are not in the same house (building), but we have regular meetings, every week. So we have ..., because there's just 2 thousand inhabitants, we have quite a well known situation about everybody who lives there, especially the elderly ones.

- Woman1 (Austria): Well, in Austria every doctor is self-employed and he's staying by himself and (with) his aids, but group practices are just starting now, so actually there's not much of teamwork.

- Man(?): So are most all GPs working alone?
- Woman1 (Austria): alone, but maybe with 2 or 3 nurses and/or a secretary.
- Man(?): Not a group of doctors?
- Woman1 (Austria): Not a group of doctors, no. But they have the possibility if the patient needs a specialist, you send him there. You may contact a specialist on the phone and tell him (about the case); but it's very isolated actually.
- Man3 (Pakistan): I think it's not very different from Sweden, with very little differences from country to country, like at my place: we've got 2 types of systems working (with us). One is private which is about 70% of care of the population, and 30% is catered (getting care) by the government. The government funding is very weak and poor for the health, so most of the time patients are seen by the private doctors, they may be primary care doctors or XXX. So there are a few things which are different, it's a deeply (heavily) populated area in all the subcontinent. But a good number of days, no, a good number of patients, and good number of days also, we work almost 6 days every week and for almost 8 to 10 hours a day and we see almost 100 to 150 patients a day on average.
- Man(?): you're alone?
- Man3 (Pakistan): yes, I'm alone.
- Man4 (Pakistan): we have independent practices. Not group practices.
- Man3 (Pakistan): But there is no social security! There is ... Funding for medical care for the population is very weak (poor)
- Man4 (Pakistan): All expenses have to be paid by the patient himself. The government does not sponsor anything
- Man(?): so everyone pays for everything. How many patients are you taking care of? Do you have a list system or something else?

- Man3 (Pakistan): a walk in clinic. (repeat) . Just come, have a chat, make diagnosis and give treatment

- M1: and how many people live there?

- M3 (from Pakistan): in our city, there are 7 million people. And the whole of Croatia is 5 million!

- Man(?): it's just a small city!

Laugh

-Man4 (Pakistan): This city is much bigger than this country (Croatia) ... I'm telling you a loose (rough) number, it has 7 million people. And the name of our city is 'Theselabard', in Pakistan.

- Man3 (Pakistan): so what I would say. It's a hard work. Its real hard work. And doing it properly, doing it good (well) is important. And as a GP I know my domain and when I see things beyond my limit I therefore, like you said, send to the consultant (specialist) and then he takes care of the patient. My domain is this much, and community is not (not there). There are no community nurses out there. We arrange our own XXX like in Austria. We've got people working, with also a team of workers with us ...

- Man(?): in your practice?

- Man4 (Pakistan): yes, and we give them the salary (?) ourselves

- Man(?): but how do you cooperate with the district nurses? The midwives? the er ...

- Man4: They all have different practices. The Gyny (Gynecologist) is different (separate), the medical doctor is different (separate), the surgical doctor is different

- Man3: most of the time, what you're saying is, the moment of nurse(ing) care is not a priority they're not given any importance at all. Nurse(ing) care is dictated by the doctor. The doctor, he advises the nurses to work on the line (instructions) he gives, and there is no independent nursing system.

- Man(?): so you can call a nurse to take care of an elderly people (person)? Or 80 years old with a heart failure or something, to take care of them at home?

-Man3: Family. Family has to take care of that.

- Man4: in our system there is no concept of nurses. Its all family support, self-support

- Man3: But you cannot engage a nurse ... its a city with 7 million people. How many nurses you will get for the elderly and for the geriatric care? ,no

- Man(?): Its all depending on the family carers ... so that's what it is ...

- GL: So the GP is the gate keeper. So, if you have a patient who's got arthritis, heart disease, diabetes? The GP ...

-Man(?) ...takes care of the whole thing

- Man3: yes, within his domain. I treat them all these patients, right from pediatric care to geriatric care but to my limit, I treat kaliphilio (?), diabetes, I treat diarrhea in children, I treat gynecologic and obstetric problems which are under my domain, but things beyond our limits, we have to ...

- GL: and if it's walk-in? do people keep coming back?

- Man3: Without an appointment; Yes, most of the time yes. But some people, they get appointments and they come, but the majority, they stay with the short term

- GL: You said in Ireland it's changing and it's an approach to a sort of teamworking. Do people think teamworking is a good idea? A sort of sharing the (medical) records with the nurses.

- Man3: Yes, it's a good idea but provided to have a lot of facilities, a lot of funding from the government side.

And if you do have to work independently, then how you can you manage the teamwork, the question is days (time). If you have to manage, by yourself, then how you can manage a team as well?

-GL: Do you work in a team *** ?

- Man5 (Spain): yes, yes, I am from Spain. The doctors and nurses are civil servants in a certain way working for the government and every patient has their own doctor and their own nurse who are in the same little team. We have bodies (areas) of 1800 patients and we always visit the same patients. or at least its different ... I'm working in a mixed area. We've got villages where there are some doctors and nurses they always work as a team for few people, because in Spain like other countries, during the last century a lot of people from rural areas came to the cities. But the problem, in some ways, is too much bureaucracy when working as a team. It's all structures. We work with centralized clinical records. All the doctors and nurses have the same program. We can see the hospital XXX departments, registration for our patients. Every day we get the patients who went to hospital. We can see the doctors of our patients care from hospital. When they are in intensive or passive patient care; but it creates some kind of stiff (unflexible) structure. Very bureaucratic. Under that we've got social services but it (this) does not depends from (on) the health system, it depends from another department and in geriatric units there is close contact with the social services because this kind of patient needs a lot of care, a lot of support mainly coming from social services. But in the cities it's a bit different.

- GL: So it's much better in rural areas

- Man5 (Spain): yes, because all the system was created from initial structures and have been modified, have been XXX. In the little villages there are few people, few doctors, few social services, but in the cities usually the social services come from the

mayor (city hall) from the XXX from 100 years But is a good system, but too much the structures people don't have the possibilities to improve and it's so bureaucratic; and young doctors and young nurses have become frustrated because always there is bureaucracy, there is no promotion, always there are problems from the government. But it is a good system, for patients too.

- GL: Do you have home visiting?

- Man5 (Spain): Yes, we have different programs from the government with data recorded, nurses have compulsory domiciliary care, we have all patient registers and we use phone calls. Last year the government tried to identify people with multi-morbidity for giving them some kind of special care in hospital or at home. We have palliative support external teams too. In Spain, the hospital tries to work outside the hospital. They have hospital home care. If some patient with multi-morbidity, pulmonary disease or heart disease, there is a team that comes from hospital to the home (we don't like to use this kind of services but the government has their rules). But they are working, trying to identify (patients needing care) because in Spain is becoming an older and older and older community.

- GL: and how do those teams from the hospital work with your teams?

- Man5 (Spain): it's only across (using) the clinical records. You can see, and sometimes you've get a phone call because some patient has been treated at home with (by) this hospital tea; you can call to the hospital team if the people (person)is going (getting) worse, try to connect with them, but there is no direct relationship with them face to face. It's some kind of 'big world' relationship? It's a good system.

- Man1 (Ireland): it's the system that we're trying to introduce in Ireland recently is to have more and more community services that are actually hospital based, so it's hospital teams coming out to the community, which GPs are generally supportive of

and in favour of in Ireland because ... it tends to be, especially in rural areas it doesn't really solve the problem, 'cos as you know, these patients and these services aren't there on a day to day basis, they're not there really when they're needed and it's not really communicating with the GP, so it's a way for the department of health to show that they are providing services. But GPs feel these services would be much better resourced in general practice; coming from general practice, and what these services are doing, the GPs are doing on a day to day basis anyway. And if there was appropriate funding the resources could be put into general practice and I think they could be run a lot better.

- GL: and do the hospital teams, do they talk to the local GPs?

- Man1 (Ireland): Generally, not. They can ring us, but we've had very little communication with them. Again there is no system of communication, other than usually letters that arrive after the events so there's no up to date information coming from the hospital

- GL (UK): In England communication is a really really important issue, in hospitals, when people come out of hospital, within the primary care teams and with the patients as well. It's a really big issue.

- Man3 (Pakistan): I think in UK, making appointments from (with) a GP is not an easy job. I've got my relatives coming from England, from London, asking for treatment. 'cos they tell me that they ask for a GP appointment, but it is never before 5 to 7 days

-Man4: I think even the emergency system is not very good in the UK, because I have seen if you go to the emergency you have to wait 2 to 3 hours I think. 'Cos I went to emergency just for an eye problem, and I had to wait there 4 hours

- GL (UK): the target in A&E is that you are seen within 4 hours , but it has perverse consequences

- Man4: Yes, if you can't sit there for an emergency, because an emergency has to be done at once

- GL: Some people arrive and A&E would appear to not be busy, but if the target is four hours sometimes you feel people wait.

- Man3or4 (Pakistan) ... *TOO MUCH TALKING AT SAME TIME*

- Man4: Yes

- Man3 (Pakistan) Answering your question for nursing care. In the social set up that you've got in some continents we're still living in joint family systems (as an extended family). So if some elderly person is sick, he's got many people around him to take care of him. So, this system is still working well.

Man(?): I understand that

Man4 (Pakistan): we do have social values

LAUGHING

-Man2 (Norway): You know in Norway and some other countries, I think of Sweden as well, I think it is... We can call the nurses to do home visits, to check out and to do some treatment at home (*cough*) without the GP. So they work together to take care of those patients at home, and of course, it works quite well.

- GL: so, you can ask nurses to go and do the home visits?

- Man2: yes

- GL: Would you do home visits?

- Man2 (Norway): yes, not very often, but three or four in a month I think. And that's most for patients with palliative care, terminal (terminally ill), taking care of them.

- Man1: What about patients who're ill who can't travel, do they

- Man2 (Norway): I can't tell but I think the... hum... in the last years, home visits in Norway has (have) been decreasing and most patients have to travel to the doctor,

because er and I think the reason for that is that you can do much more for them in the office, lab tests and everything ... So the amount of home visits is just going down, but we are still taking care this 'hard core'. That's ... the number has decreased also because the nurses are taking care of them at home, in the team with us, so that makes it more easy, for the people to stay home and us not to go on visits

- GL: do you have social services as well, who go out?

- Man2 (Norway): yes

- M(?): is that XXX working? XXX Nurses have the competences enough

- Man2 (Norway): yes, there very clever. The psychiatric and the oncology and *O-kites* (?) are also working as a team, and ...

- Man2 (Norway): I think the patients are quite satisfied with that as well, especially when people are going to die at home. We are there often to give them terminal treatment *Noise*... to make them feel safe, I think that's the most important thing

- Man(?) What I want to know, is that do the relatives of the dying patient they don't (do they) ask for high profile treatment? They are satisfied with the nursing care.

- Man2 (Norway): Yes, and the nursing care together with me, or the other GPs. So quite early when we are seeing how it is going with the patient, we take the decision about ... to treat or not to treat, or to just let them die at home.

- GL: But you've got very highly trained nurses in Norway

- Man2 (Norway): yes we have. I think it's the same in Sweden. I'm not sure, I'm not talking on behalf of you but ...

- Woman2 (Sweden): I believe so. We have some er ... home visitors. Not often, but I believe sometimes. We have, and usually we need to evaluate the patient with relatives, talking about the situation. It's working really well.

- GL: in England, most GPs are in teams now and you make an appointment and, you're right, sometimes you can wait a long time to see the GP you want to see and even to see any GP you can wait a week or 10 days; but there's a shared record. But we don't have the same highly specialized nurses that you have, in our rural practices. Everything is working like a team, but there is an issue about getting an appointment. But for everybody over seventy-five in England they've introduced named GPs; so usually in a practice one GP will take responsibility for older patients and somebody with different conditions always has a named GP to go to, so you've got some better continuity; and that's what they're trying to introduce in this(cut off)

- Man(?) ... and also I think that the number of home visits has been decreasing, there are , sometimes I have to move (travel) a hundred and fifty kilometres to see a patient so it's quite time consuming, so, so...

- Man1: we still do a lot of home visits in rural Ireland, but it's been decreasing as well, because a few years ago we used to get paid an additional fee depending on how far that the patient lived from the practice, but that's now been abolished so and we used to also get a fee for a home visit, and now that's been abolished, so there's no fee for attending patients, so GPs have had to try and restrict it a lot, so in my practice with about two thousand patients, I think we have on average maybe one or two home visits each day by the GP. Because it can be 20 to 30 Km to where it is, it's quite time consuming so we usually leave a block of one or two hours in the middle of the day for lunch and home visits.

- Man(?): Do you find those home visits necessary?

- Man1: a lot of them... hum...

- Man(?): or is it more convenient for the patient?

- Man1: yes, there's always an argument as to whether they can or cannot come, so our secretary takes the calls and she usually tries to persuade people to come to the practice. Usually they would tend to be for bedbound older patients who cannot come. You know, it's usually only for patients who are too sick to attend or too immobile to attend. We don't allow home visits for patients without transport. We say if you can travel you have to make your own way. But the contract with the government is that you provide care whether that be at home or in the surgery so you can't refuse a patient ... *coughing*...

- Man(?): so it's more or less pre-paid?

- Man1 : yes, there's a capitation fee, so there's a fee per year for all people, so if a patient insists it's very difficult to refuse to attend but GPs have tried a lot to reduce home visits because there just isn't the time really, without financial reward for it

- Man2: we get paid for home visits, and for time we use, and for using the cars

- Woman1 (Austria): in Austria GPs get paid for the home visits and for the kilometres used.

- GL: That sounds very generous

- Man(?): That sounds reasonable I think

- Man2: Norway is a rich country, so this is for the north of Norway, they still have money to do this for us

- GL: so do you get paid for the travel?

- Man2: yes, and the time and for using the car, I have been driving my car and been paid from the government to see the patients. And, you know, everybody pays a little bit and the government pays the rest for each consultation, ok. And until they reach a certain level after 2000 Norwegian Kroner, it's free. So, it's a good system.

- Woman1 (Austria): so, in Austria the doctors are not paid by the government but by the they get paid for the work they do by the social security. Not by the government and not the number of patients they treat, but each thing they do, each consultation ...

- Man3 (Pakistan): do you have walk-in clinics?

- Woman1 (Austria): and, it's walk-in

- Man(?): in the bigger cities

- GL: is it the same in rural areas in Austria?

- Woman1: Yes, especially in the rural area

ALL TALKING AT THE SAME TIME

Man(?): its getting popular these walk-in clinics

- Man1 (Ireland): In Ireland it was traditionally walk-in clinics until recently. Most people (GPs) just to organize the day have an appointment system, but most people get an appointment very quickly.

-Man(?): that's good

- GL: What strikes me is how different it is. From listening to all that, what do you think would be good practice for looking after people with multi morbidity?

- Man1: I think good nursing care is very important, I think it sounds like one of the last real bridges to reduce GPs work load and probably better care for patients, with more continuity.

TOO MUCH NOISE FROM OTHER GROUP

- Man3or4 (Pakistan): social services is an issue because where we work, in XXX there is multi-morbidity patients... XXX... and other kind of multi morbidity problems. Sometimes the community manager (?) takes care of people with a stroke. Doctors can do a little help in this kind of problems. Nurses and social services have got an issue with this kind of problems because of the growing number of people every year,

people becoming older and older. I don't know in twenty or fifteen years what will happen with all these problems. It will be a social ... sociological problem difficult to manage. It is different from these countries where there are a lot of young people working, in Europe... XXX ... their prospective are very er

- GL: who is going to provide the care in the future?

- Man3 (Pakistan): I think in fifteen years, I don't know how, the government will manage these problems with older people and multi morbidity, home care. I think we need a change in the health services. If we can say the services XXX... I think it's a new kind of relationships because young doctors want to be doctors but in the future I think they will need to be different from the doctors nowadays because like timecare, XXX care people, consulting, I don't know.

- Man4 (Pakistan): I admit that the community nurses can provide a good professional-care, but the question is can they give the good social and emotional care to the patient which they (the patients) demand?

- GL: some are very very much... *noise...two people talking at same time*

- Man3 (Pakistan): demand too much care ... can the community services can they provide the XXX officially they will be strong, I admit. When the patient is in homes, they're in home they need emotional care better professional care.

- GL: yes, yes

-Man (?): I don't think that the nurses the community nurses, the home nurses are going to take over that important part of the family care xx

- Man3or4 (Pakistan): ... emotional care at that stage ... they need close relations at the time

- Woman1 (Austria): but our families are so small, there's ... very often there is no family there

-Man3or4 (Pakistan): if the family have no time to take care of old patients XXX that is a problem.

- Woman1 (Austria): the families give much time if they're around. But if they are in another part of the country how can they. We're scattered, we're small families

- GL: I think it's really important, the aging population, work force and how is going do XXX and when people have small families, and they're on their own.

- All of them: it's big differences

- Man2 (Norway): you ask what will happen in the future ... In Norway there has been changing of all the hospital structure and they are transferring sicker and sicker patients to the primary health care. And in the future that's quite challenging because then you've only good nurses and a lot of (or: not a) good GPs to take care of your patients who earlier were hospitalized. So this is quite a big change in Norway so it's very challenging, especially in rural areas, to get GPs to stay for a long time to take care of all those patients, it's a complex decision.

- GL (UK): well you have the health service, and we have social services and they don't really work together so there is a lot of work, trying to make things most streamlined and integrated because from the patient's point of view, the argument is that if you need to see an occupational therapist you don't mind if social services pay for it or the health service pays for it. But at the moment, you can have both, or nothing at all, because people sort of fall through the gap. So there's a lot of work trying to get people to work more closely together doing exactly what we're talking about; But the same as in Austria the families are scattered. People haven't necessarily got a local care giver, so they're trying to use what we call 'the voluntary sector'; And if you have charities where you have some employed staff and then volunteers who are trained and they'll provide a befriending service, or they'll drive people ... social things so

they're not isolated. But, again, it puts a burden on the community because they're trying to do exactly the same thing as in Norway, discharging people from hospital earlier XXX at home and to try and do it differently. They're trying to integrate, the whole package if you like, to try and make it easier for the patient so that the patient has the confidence that they will have the support they need. And you have this sort of concept of volunteers.

- Man1 (Ireland): In Ireland XXX services are provided through voluntary organisations; The state funds voluntary organisations to provide the service instead of providing it directly. hum ... kind of religious organisations, brothers of charity, would provide home care or bandage care ..and although it's .. really voluntary, its 's being paid for by the government, but a small amount of volunteering ...

- GL: I think that in the UK they see that using the voluntary sector as a way of paying less for what you get at the end

- Man 1: XXX.... are coming. That's a cheap way to have this service. People aren't directly government employees, they don't have to provide pensions and all that

-J: so do you think it works?

- Man1 (Ireland): I don't know, I think it often provides a good efficient service, but it means that the service is a lot more .. er There isn't as much coordination ..its different in different areas ; I think having a more structured service through the health system would be better.

- GL: Comments?

- Man(?): not this system here. it's not the XXX it might work in big cities but in rural areas no

- GL: You don't have voluntary groups

- Man(?): ... organization, not usually people who are XXX care is difficult. These people (volunteers) take care of other poor people XXX from the community support structure ...

- GL: One of the questions is about whether there's enough funding. For Norway, I see you're reasonably well funded by the government

- Man2 (Norway): Yes, it's always been the question that you want more. You can put as much money as you want into the health system, Its always a question about more. I think it's interesting to ask: are they using money on the right things. And er...

I'm more concerned that people have to wait to see a GP for 1 week, 2 weeks, , weeks, 5 weeks ; because the earlier you have access to a GP ... You're increasing the anxiety for illness, so it's problematic, really a lot of worry, because sometimes when you see a GP you are healthy after a week but if you stay at home ... it takes 7 days, so the number of consultations its XXX not the amount of the health service actually

- GL: There's a thing about expectation by the patient as well then, isn't there

- Man(?): Expectations are XXX like that and the patient worries there will always be gaps, it doesn't matter how much money you put in, I think

- Man1 (Ireland): Time is a great healer and if you think you can ... You just don't have the time, and I think if you've got the resources to bring people back, you know, and if you know you built a relationship with your patients where you can say : if it gets worse then you'll have to see me but if you're busy with no slots ... its very difficult to do that. It depends if people are paying to come and see you again or not. If they pay to see you they want treatment, if they haven't paid to see you then sometimes they won't come to see you again

- Man4: Its not only treating the disease its treating illness, illness of the patient, and it's XXX ... So you wait for 5 days for appointment from the GP then

... Its not worth it

- Man1: With us we've two systems of public and private, for both public patients you get a capitation from the government, that's about 40% of our practice and that's means-tested so people who don't have to have the financial means to pay for it. The rest of the population needs to pay each time they see the G P. You do notice that the insurance, it does influence your practice. If somebody's paid 50 euro to see you and you think it's a cold or a viral illness try to tell them they're fine, go away, just take it easy, is difficult. Whereas if there's somebody who hasn't paid to see you, then you're more comfortable ...

- Man(?): But you want more from this ...

- Man(?): You can put as much money as you want into the health system, there's always a question about more. Its always a question about more . I think it's interesting to xxx are they using money on the right things?

- Man (?): (*REPEATING WHAT HE SAID BEFORE*) I'm more concerned that people have to wait to see a GP for 1 week, 2 weeks, , weeks, 5 weeks ; because the earlier you have access to a GP ... You're increasing the anxiety for illness, so its problematic, really a lot of worry because sometimes when you see a GP you are healthy after a week but if you stay at home ... it takes 7 days, ok, so the number of consultations its ...

- Man(?): just a cold, just stay at home. Come back and see me again if you're worse, it's quite difficult to ...

... are you trying to get more money out of them; Sometimes the patient who's paying to see you is getting less of a service than the patient who isn't paying to see you.

- GL: He gets more time

- Man1 (Ireland): No, same time, same appointments, same everything

- Woman(?): Not more talks. Well Actually I'm not a GP in this social service system. I'm only private and people only pay, but what they get is a whole lot of time, and personal relationship. One hour with the doctor (me) whereas the time is 10 consultations with a doctor (GP) maybe the outcome at the end is the same, or maybe It would be interesting to compare the health outcome of people who are, the older spectrum of illnesses that I deal with (*TOO QUIET*)

Man(?): How long are your appointments in Norway?

- Man2: That depends. Sometimes I use 5 minutes, 10 minutes, half an hour. That depends

- Man(?): So I've been working there for 35 years; So I know all the

- Man(?): So I can see what the ...

ALL TALKING AT THE SAME TIME

- Man(?): Here we go so its quite tame really, the number of minutes I get;

- GL: In the UK it's 10 minutes;

- Man(?): It's 10 minutes with us too

- GL: If you see a nurse-practitioner you can get 15 minutes

- Man(?): Sometimes 10 minutes, it's much more than enough; But sometimes it's absolutely not

- Woman(?): Can you decide to spend more time?

- Man(?): Yes, I look at the list for the day and say if it's ok. Its flexible

- GL: it comes back to

NOISE

- GL: Then we've got to feed-back. So we've recorded it and I've made some notes.

On the whole you think teams are a good idea

- Others: Yes, yes

- Man(?): Necessary

- GL: and shared records

- Man3or4 (Pakistan): How can you manage the people like us, you have too much crowded populations and you should appreciate our effort to deliver the services. Because the teamwork is there, but (and) you have a lot of parts available. We people are serving (working) at minimum cost

- GL: Do you think having nurses in a team would reduce your ... *COUGHING*

- Man3or4 (Pakistan): Yes, certainly. All these things are needed in developed countries, but underdeveloped countries are being ignored definitely. No people is bothered to discuss their methods, their problems. The world conferences should see (look at) the problems of everyone. Nobody's hearing about the problems of the underdeveloped countries, like us

- GL: That's what the rural working parties should be doing

- Man3or4 (Pakistan): Everybody discusses the problems of the New Zealand government, of the Ireland government, of Australia, UK, Ireland. We're determined to tell what we think

Look at the data from developing countries; The masses, the volume, the diseases, the volume of work

NOISE

- Man(?): A lot of work has to be done

- GL: I think it's really difficult using Europe. There's Norway, then you've got somewhere like Croatia, southern Italy, where it's just so different. I think the Balkan countries the primary care isn't developed; They probably need ...

- Man(?): ...XXX

- GL: I think that is something we can give as feedback to the working party....

- Man(?): this should solve the problem of underdeveloped countries

- GL: it's so different

- GL: I used to work in the food industry as a food scientist for the government, and we worked something called the codex XXX

anyone heard of it? It's whole focus was to establish international food standards, and you would query why Norway, UK or some of the more developed countries went. And the whole idea was to support countries who were developing. so that the UK would go to make sure a) that they could sign up to the standards, but also to help make sure that really it was something that really helped the food industry across the world raise its standards, in a way that's what we're talking about here, isn't it?

- Man1? (Ireland): It's so difficult to do in different countries because the health systems are so different. The funding being available is so different; the patient expectations, the social culture etc are so ... What works well in Norway mightn't work well in the UK. What works well in UK mightn't work in Pakistan. I don't think you can compare

- GL: You can't, but there must be some core principles that ... I just thought that. . I'm not a clinician, its probably very eary for me to say, but in just thought that some core principles that you could develop and provide mentorship or something to help different countries who are at different states of development. Yesterday Sarah S*** talked about Guiana. That used to be British Guiana, apparently, when the British left, they just walked out, and so in 50- 60 years they haven't got any money, and the health system just hasn't changed with the times. It sounded really dire, didn't it ? And so Canada is involved in actually trying to support the training of medical students and how the health service is shortly developed. It's really what you're talking about, isn't it.

- GL: So what do you think is the biggest challenge for managing patients with chronic illnesses?

- Woman(?): That's there's an aging time-bomb

- Man(?): Funding

IMPOSSIBLE TO HEAR THEN SILENCE

- GL: Well you'll all have to contribute. We've done a quantitative analysis on all the questionnaires, but the qualitative comments, what's free text, that's the next stage; and so these comments will feed into that.

- Man(?): But the biggest thing we focused on here today was who's providing the care ... GPs versus nurses

That seems to be the big issue within the group, who's actually... who's actually providing the care whether it's GPs, nurses, hospital beds

- Man(?). In Norway, are all GPs are trained for palliative care?

- Man2: More or less, yes

- Man(?): I think the great challenge in the future are of course the funding and also to educate the GPs, and there's this ... good enough so they can take care of a large amount of elderly people that are coming. And that the amount of elderly people that the hospital took care of earlier, that now they're sent back to the primary health care. So we need to face that problem and educate ourselves

TOO QUIET

- Man(?): there is the problem of home visits. I know people, they cannot take care of the elderly ...

TOO MUCH NOISE FROM OTHER GROUP LAUGHING

- Man(?): Home visits, most of them mostly can be done but the nurses, as part of the team with the doctor. And I don't like the idea that the hospitals are doing home visits....

That's very strange for me. That's absolutely ... starting in the wrong direction

- GL: We don't have hospitals providing, sort of the care in the community, but they're doing exactly the same, as we were learning earlier, having much shorter stays in hospital so the work load at the local level is much much higher.

- Man1(?) (Ireland): Hospitals are judging a lot of their performance now on length of the hospital stay. So their feedback to the department of health is that, you know: "We've done a hip replacement and the average length of stay there has gone from 9 days to 5 days". It seems to be that they're using it as a marker of improved quality of care; whereas in fact a study last week showed that shorter hospital stays following hip operations increased the morbi-mortality of those patients. So, shorter stays aren't necessarily a good thing. And I think GPs in the community see the effects of it a lot more

- GL: See, In England, there's a penalty if people are readmitted to hospital within a certain time, so you've got that balance against discharging earlier and earlier But if you discharge too early you get a penalty ... the risk of readmission is more ...

- Woma1(?) (Austria): Who decides the penalty?

- GL: The central government. But it's very odd. We talked about A & E delays, there's delays in admitting patients. And although they want to keep patients out of hospital they also get paid for having people in hospital

NOISE

- GL: Thank you very much everybody

STOP

Group 2

Chronic morbidity in rural areas: individual health project, polymedication and end-of-life care

- Group Leader 1 (France): So we have divided the topics in two groups; we would like to speak with you about the patient's care, individual patient health projects and problems of compliance, solutions and problems you encountered in your practice and the problems of polymedication and also the loneliness for patients, for old patients and problems of caregivers.

- Group Leader 2 (France): Okay, who wants to speak? ... Don't be afraid!

- Woman1 (Ireland): Okay that is right. One thing I was just going to ask would be ...if you would find it useful to get more information from the countries that you already have. I saw the single lonely pin in Ireland: and that was me! (laugh)

Would be useful for us to go back to our countries and gather... and try to send questionnaires to more GPs in the hope of getting more responses, and forwarding them to you. Would that be useful?

- GL2: The questionnaire is always active now, and you have the links and you can follow the links to all colleagues and they can add data.

- Woman1: It just might give you a little bit more information. Mine is only one opinion from the country....but my practice would be...

- GL1: The questionnaire is a form of er, er ...data gathering, but the description... perhaps we could add some more details.

- GL2: Because the questionnaire is an open questionnaire. We have some open questions; as it is difficult to describe precisely, accurately what happens and what are the problems. And sometimes it is interesting to have a workshop to exchange.

- Woman1: That might be something that everybody could do and then you have more to work from. It's just a suggestion

- GL2: Other?

- Man1 (Spain): Yeah, my name is ***, I come from Catalonia, I work in an area north of Barcelona. One problem we are encountering is kind of polymedication and when people are discharged from hospitals, in order to conciliate the medication, they carry on from the hospital with one. Now we have quite a good electronic system that allows us to see the medication when they are discharged from the hospital. But this is still very time consuming. If you have the XXX then it goes to primary care and you need a lot of time to talk to the family. And just to make clear what medications they take (in) and what not. One thing I would like to discuss here is if in the other countries, is it the same? i.e conciliate the medication when they are moving systems, from hospital to primary care and from primary care to hospital.

- GL1: Is it for a same medication which is changed to another or is it for added medication?

- Man1 (Spain): Well. Sometimes they add medication, and they stop. I don't know in other countries what happens, but we have like a 'retain center' ...XXX...the same medication as usual ...XXX... I think it is quite a lot of problems happen with this change because sometimes they stop the medication but they don't write it down and...mainly with people taking anti-coagulations and ...XXX...

- Man2 (USA): I practice in the US, so it is a little different from what you are doing with a data correction here perhaps but the problems are the same. For years in my practice I've had, patients that will see a specialist and come back with new medications. So my instructions are "every time you come to the doctor, put everything in a brown sack and bring it with you" So that I can see everything, and we have the nurses go through

it and update that. Now, I've practiced for 40 years without computers. Now the little rural clinic that I'm in has a computer and the nurse puts in all the medications. But she doesn't update them. Every time they come to the door (clinic) it takes that 2 or 3 minutes to pull the thing up on a computer and check "is he or she still taking this / this / this or this. And if the nurse will do that then things stay current (up to date), if they don't do that then you get a long list of things they've been on but are no longer on. So the challenge is to have some accuracy in your medication. Er .. One of the problems we have in the little clinic that I'm in now is that we are 60 (85Km) miles away from a hospital. On the west side of Yellowstone Park and in the mountains, and we're about 20miles out of West Yellowstone; a little area called Heyden (Halla) Park about 2200 meters in elevation in the mountains. And many patients that have retired there and live there, they elevate (?); they do not stop at our little clinic for care unless it's an emergency. They will leave us, drive 60miles; and go see the doctor at (in) the valley. And then the only time we see them is if something acute happens. Andso we're trying to teach the people in our area that they should come to us first before going to the valley. So that we can have their medical records and answer their questions. And this is a real challenge.

- GL2: You are not a gate keeper, as are GPs?

- Man2 (USA): No... the American system is not... you do not have an assignment to a gate-keeper or physician. You are totally free to select who you want to go and see. But, as generalists what we are trying to teach them is: "see your primary care doctor first; don't go to the urologist, or to the surgeon or the cardiologist first. See your primary care doctor first". .. It's hard because they get confidence in the cardiologist and that's the only person they would see sometimes.

- Man3 (UK): I work in UK, but my feeling is that ... about the polymedication. Once it is prescribed it goes on and we do not give enough time to re-evaluate whether this medication is necessary. So I feel if we could ...XXX, give more time to look at all these medications and see whether the patient needs it.

I think if I am right there was a trial done in Ireland; and it is (was) a hard (strong) conclusion that we could do it, lot of ... limit ... less medication with equal effects. ...XXX...

- Woman1 (Ireland): I think if we are looking in Ireland, in some ways, first of all the GP is very much the gate-keeper. You cannot get an appointment with a specialist without going through the GP. So if you want to see a cardiologist, respiratory physician, anybody, you must go through your GP and make a referral. The down side of this is that it takes a long time to get these appointments but you must go through the GP. You cannot just phone-up the specialist and make an appointment. So it's a good thing. Another thing we use, we have a medication card, which is like A4, folded in three, hard (carton). We use those for a lot of people to write all of their medication.

It takes a little bit of time the first time they do it, but then they have this card with them and they can bring it to the dentist, to a they hospital appointment, to the GP, and they have all their medications ...(written down). . Personally, I would go through them and say what each thing is for. They don't understand the big names, so say for lansoprazole I write 'stol', and so...You know ...XXX... blood pressure, so put it in a simple language. What each tablet is for and so that they understand. It takes a bit of time to do it the first time but then it's very useful for them to know, and then if anything changes we just change it. . Also, any medication that is prescribed for medical card holders must come from the GP. So if medications are changed at the hospital they must come back to us to write the prescription. Now, very often we will write a

prescription that the hospital wrote. And they say to us; no you don't need that .. or they'll change the ppi, or change the blood pressure target. We'll know and say: "you were on that before, your ankles got swollen, I'm not putting you on that one, we'll go back to the one you were on before". So very often we will make those decisions; after the hospital has decided what they should be on. But I feel as primary care physicians we know our patients better, we know what works for them and sometimes they (the hospital) discharge them on huge amounts of analgesics without explaining to them what PRN means. So you have patients coming in, spaced-out saying "well I'm taking 100mg of XXX.

"Do you have any pain?" "No" "Okay... You don't need to take, it. Stop"

So I think in Ireland we have a fairly good system with regard to knowing who our patients are, and what they're on, and managing their medication.

- Man3 (UK): Let's clarify, there's no scripts (prescriptions) from the hospital?

- Woman1 (Ireland): No. They have to come back, if they're a medical card holder they must come back to us. Now, a problem the patients can have. We do have a two tier system, which isn't perfect. Private patients can come back and go to the pharmacy with the prescription from the consultant. But at some point they will end up coming back to us; and we'll say: "Well you're on that now, we'll change it in our system". Practically all GPs are computerised as well and 100% of pharmacies are computerised. So, it's a fairly good system, It's not perfect but it's reasonably good. We... er ... still have lots of problems.

- GL2: Any other opinion?

- Man4 (Romania): My name is *** **. I am coming from Romania. A few years ago, I think 3 years, I have a colleague who was (going to) working in France. On one morning she called to me "****, I have here one patient with 18 drugs" Wow! What has

happened with this patient?... because my colleague is in a very difficult situation to manage this situation. the ...

In Romania we have some situations with patients with multi morbidity chronic diseases. And we decided on a schedule (regimen/prescription) of drugs to (for) the cardiologist, one by the neurologist, to one by the dermatologist, and some medication is similar(ly); so for example, for hypertension/blood pressure, the neurologist prescribes Enalapril and the cardiologist prescribes the ATACAN or another drug.

The role of the GP in Romania is to make er, er... correctly a schedule of drugs, for all pathologies, and (that) do not have interactions between drugs. That's because because it is possible to have patients with drugs for blood pressure / beta-blockers but the patient may have also COPD or asthma. This is the role of GPs in Romania. I don't know what is the situation in other countries.

One of the other issues in Romania is discovering the illness in an early stage, because. and not receive the patient with cancer in a late stage. And we don't have screening programs, (that are) efficient. This is our problem.

- Man5 (Canada): Good morning my name is *** **. I am a practitioner from Canada. I work in British Colombia, In a small town at the north end of Vancouver Island. We're about 230Km away from a secondary hospital. COUGHING we have a ...XXX... hospital and about 8 remote 'outreach' clinics that we visit .. (INAUDIBLE ...)

I think that the problems you have outlined are very similar actually, as far as the chronic diseases go, specifically for the polypharmacy. We work very hard to try to reduce that along the same lines that go on in Ireland apparently, ... er... It is very time consuming, we run an electronic medical record and we have to put those drugs in ourselves and change the things and try to sort out whether they have been changed or ... So that takes a lot of time, and sometimes I think too much time. Whether we

could use a nurse to do that, that's possible. We haven't done that. We'd have to pay additional money to do that, so that's an issue. But maybe it is a solution. Maybe it's a worthwhile economic decision as well.

I want to make comment about the types of chronic disease as well. I didn't see any references to addictions, or, I think you mentioned psychiatry. I think myself that detection XXX so all of types, whether they're obvious or not obvious addictions and I think it underlies an awful lot of what we do in general practice. I've estimated around 60-70% of ... it has a hand in that number of patients.

So, it is not immediately obvious all the time. So I think it is something we need to spend a bit more time thinking about and looking at.

- Question: Do you include eating addictions and smoking?

- Man5 (Canada): Oh absolutely: gaming, sex, too much religion... all things.

(LAUGHING + INAUDIBLE COMMENT OF AN AUSTRALIAN PRACTITIONER...)

- GL2: In France we have a big experience about alcohol.

- Man5 (Canada): Yes, indeed, yes.

- Man6 (Australia): I am *** **. I work as a locum these days in remote parts of Australia in a hospital situation I work a GP and anaesthetist. Similarly, compliance is a really major issue particular among the indigenous populations who often suffer from chronic, cardiac /heart diseases and also diabetes, and also addictions... Huge problems in those areas.

And just a couple of things that are done in Australia that I am aware of ; one is there is a National Health supported scheme for pharmacological review of drugs. A GP can ask a pharmacist to do a review of the drugs and make suggestions, which is sometimes helpful. And I guess my other ...yeah... XXX... you mentioned costs of drugs. It seems to be XXX that a drug will come in and it's a fantastic drug. And

invariably within in a few years there is a more fantastic drug, and a more fantastic drug. And invariably a so Simvastatin is replaced by Atorvastatin which is replaced by Rosuvastatin. My feeling is that doctors / GPs need to be aware of the National Guidelines and follow those rather than the latest fashions. Because I think they do lead to a XXX of unnecessary drugs that have unnecessary costs with them, and I ... So Australia has a very good system of therapeutic guidelines that are reviewed by a panel every 2 to three years in different areas, It's available in almost all the hospitals and on all the computers in General Practice. But only about 30-40% of our doctors, as I understand, follow that. But if we could have all the doctors following that, I think we would be a lot better off for things like antibiotic stewardship and other areas too. So, there are just a couple of things that are done in Australia, but we have no answers to the compliance and cost issues. I am sure that Australia is just like Europe and North America.

- GL1: that is really the main problem of this study: in all countries all of the questionnaires ... that is the main problem... the problem of adherence / compliance. There are synonyms.

- Man2 (USA): Yeah, In the words of Sir William Osler: "use a new drug as often as possible before it loses its effectiveness".

- GL2: And have you some problems with drugs about cancer and oncology because in France – for example – the prices of the drugs increases. For example, for a lymphoma you can have more than 50 000€ for a year of treatment for a patient. Is it the same problem that you have in your country?

- Answer/Man6: And often the decisions about which drugs become supported (reimbursed) are done more on a political level than on a rational level. So somebody is gains a lot of sympathy for a particular conditions and they've heard that a drug will

work and they'll start a national campaign and ... It is very hard for the politicians to stand up and say: well actually the evidence isn't in for this. Evidence-Based-Medicine isn't practiced at the political level in Australia, I don't think.

- Answer/Man2 (USA): Treatment for hepatitis C is another example. In the US it is about 60 000 \$ a year for that. Yet, where are the highest number of people with hepatitis C? They're actually in prison and so you get caught between a rock and a hard place: if you don't treat them the you are denying them good medical care. So I saw a thing in a newspaper a couple of months ago, the state prison in Idaho where I practice have requested from the legislature 12 million dollars to treat the people who are in prison that have hepatitis C. You know.... It's interesting, there are some extremely expensive drugs. Chemotherapy drugs, and then hepatitis C treatment.

- Woman2 (Australia): (*INAUDIBLE*) it's actually a public health issue. It is not just... you need to treat the person, but in a prison system with a high incidence of hepatitis C you'd looking at a public health thing. ... I just wanted to make a comment. You talked about in Spain with the interface ...the ...um interface with different IT systems and being able to access... um ... the information about drugs used in hospitals...

In Australia we have a mixture of public and private systems and they do mesh together in ... , to a ...XXX ...degree. One of the big problems is that often the IT systems used don't mesh together and there's a big privacy issue. They won't allow ... Sometimes they won't allow access to hospital records and .. for an outsider because of the privacy issues, and we have quite strong privacy laws. I'm sure that's true in other places.

ALL TALKING AT THE SAME TIME WITHOUT MICROPHONE

- Man1 (Spain): (*INAUDIBLE*) with private we don't have and ...XXX... my access to hospital medication ...XXX... to accept ...XXX... every time for drugs ...XXX...

- Man2 (USA): (INAUDIBLE too...) Is there electrical? ...XXX...

- Man1 (Spain): Now we have, even though you have to check it because in hospital centres they don't accept the ...XXX... as we do checking all the medication. when they have a medication with the new medication they still have to check that we don't have any duplications or any interactions.

- Woman2: In general, do patients in other countries pay for their medications at all?

TALKING WITHOUT MICROPHONE ...

- Man4: In Romania, some medications, for diabetes / cancer / and other illnesses ... is free of charge. But for current medication, like hypertension or respiratory diseases, it is ... just part is free of charge. Yes. Some 10% is paid for from the patient, for the child for example. And for hypertension there is 2 groups: in one the patient pays 50% and one patient pays 10%, depending on the international ... er ... nomination of the drugs.

- Man2 (USA): In the US, I'm on MEDICARE now (INAUDIBLE). And I am coming up on my "donut hole": you pay for a while and then there's a hole where the insurance pays for a while and then up to about 2400\$ and then from 2400\$ up to 4900\$ you pay out-of-pocket (yourself). And at 4900\$ it kicks in and pays again. I am diabetic and other things and take about medications worth about 800\$ per month. So I am ... in May I hit my "donut hole"; I'll be in October before you get to the other side, it starts to pay. So every month for me it is 800\$ for about 4 months that I have to pay out of pocket (myself). That is just the way the system is designed. I hope they do away with the "donut hole" even if they pay only 50% of the cost of the medication.

- Man3 (UK): In UK, we pay high ...XXX... for one item roughly ten euros, but it is those above 60 don't pay anything. Below 16 don't pay anything. And also, those who are on benefits / don't have jobs and... they don't pay anything. And also, some diseases

which need life-long medication like diabetes. And thyroid, that sort of thing, they don't pay anything. So it's quite good and in some of the parts of the UK, I suppose in Scotland: they don't pay anything. United Kingdom pays, and if you need lot of medication like doctors XXX they can do a yearly card which is a lot cheaper, probably around 120€ and then you don't pay anything.

- Man7 (Germany): My name is *** ***, I am from the University of ***, chief of the department of Family Medicine. And ... Polypharmacy is a big problem in Germany, mainly with the elderly and ... about 20-40% of these elderly may have chronic diseases have more than 5 pills that is polypharmacy. And we have made in the last year with a couple of doctor groups, quality circles, focus groups about topic prioritisation in polypharmacy, after for elderly people, after discharge of hospital. A big problem in Germany if the patient came from the hospital to the family doctor, they got new medicaments and ... only the family doctor has to decide what happens now. We made first a qualitative step with these doctor circles of family doctors in rural areas of Saxony XXX, and try to identify criteria of prioritisation. Because there are not any guidelines which help the doctors. One point was very important for the doctors, patient's safety, and quality of life. Many points of the patient's view, that was very interesting. And now we are studying with some more representative quantitative research and we are working with ... er ... this special patient's description / describing and then to ask the patient, 65 years old, this diagnosis has happened, and what will you do with this patient?

And now I want to know in your countries, do you have any experiences in research in rural areas with prioritisation in polypharmacy?

... ? No

- GL2: Who has system like quality circles or peer review in your experience?

- Woman: No, haha. (very difficult) Not personally experiences of peer review but we are systems (not audible) ... inside...

- GL2: Any comment?

- Woman2 (Australia): I'm from Australia, You guys might have to help me We've got the national prescribing service which is a national body that ...um ... sends out regular, say quarterly, newsletters about evidence-based guidelines on prescribing. And they pick a topic. And the most recent one was hypertension and they picked the topic and discuss with us current guidelines and appropriate use and compliance. And it's followed up with ... there's a lot of online learning, this is associated with it and face-to-face practitioner visits. So it's a very useful resource; but I would very much appreciate someone to help me prioritise the medication and also with the elderly, how to withdraw, when to withdraw, when to cease a statin, it's very difficult. You just keep on adding on. We're all computerised, what most I would say in GPs are computerised Our computer system doesn't necessarily talk to the hospital's, but we do get discharge summaries, very probably the patient is handed the discharge summary. And we ... so with both the trade and generic name and a reason for prescribing. So, it's very easy for us to develop a list of medications taken and reasons why, and update it very very quickly. We can also see on our software: we prescribed for 6 months or for 11 months and if the patients are coming in too early or coming in too late. It's very clear they've just not picked up their prescription .. 'cos we can see it. So that assists us with compliance and not using it.... Begs the question: "why have you not asked for XXX what's happening?" But you might have more to say

- GL2: Okay, we've just we spoke about drugs and about quality. Can we speak about caregivers in rural areas, and who, and problems with them? Is there a solution that you can found? Is it like in Africa, living with the family? (*INAUDIBLE*)

- GL1: Especially for chronic diseases, especially for elderly people?

- Woman1 (Ireland): From where I live, in the west of Ireland, we have a high elderly population and we have a huge problem with caregivers. We find with a lot of people who have returned to live there, from sometimes other parts of Irelands sometimes ...XXX... sometimes the UK. They've had their little dream of a cottage in the west of Ireland forever, and they've retired there in the ...XXX... Some of them can't even drive. We have no public transport, zero, where I live. There is one bus a day to the local town, that is it. There is no public transport worth talking about. Many of these people live in small little by-roads up a hill and finding people to give care to some of those is a huge problem, a huge problem with a lot of house-calls. We have a system of home care packages but it is not enough, it is not enough with people going in for maybe an hour in the morning and an hour in the evening to do basic care, washing, maybe administrating medication. And there are very set guidelines as to what they can do, as well. They can't actually give them the medication; they can just suggest that they take it. The rules of regulations are ferocious; They are not allowed to do their shopping, even though that might be the most practical thing that the person needs. There are just very strict guidelines. And we have families that .. who really don't want to know. everyday of the week I have families on the phone saying: "well ...what are you going to do about it, doctor? I know she needs care, what are you going to about it?" It's very difficult not to say: "Oh ...she's not my mother... I can't live-in with her, you know that" ... "I have a job, I am in London, and I can't XXX ... what do you expect me to do about it ?".

So we have a huge problem with care. We have one nursing unit, in the area for 40 patients. And we have a respite system where four people at a time can go in for a week or two weeks to give the caregivers a break. But we have a lot of elderly people

living alone with very little input from community. We have a very good day-centre as well, and we have a bus service of volunteers within the community supporters to bring them to the XXX. Without them I don't know what we would do. Because ...XXX... , one given a meal, the doctor visits, the nurse visits, the social activities for them: it is a fantastic service, if we didn't have that I really don't know what we'd do. But we're running on a shoestring all of the time. I don't know what the answer is. The government doesn't seem to want to listen to GPs on the ground when we say: "we need more home care packages because without them patients end up inevitably going into hospital for something that could be treated at home". And, but we can't manage it, we can't go in to give ...XXX... three times a day, or whatever, for something so. It is a huge frustration where I live and that will be shared by a lot of other GPs in Ireland. It is a huge problem.

- Man1 (Spain): I work in an area, it's rural but it's not very remote because we are about 50 min from a hospital. So they have a service of day hospital and you have to send somebody for IV antibiotic, you can do this. They can go three times a day and they give the antibiotics and they can remain at home. We are lucky that they are not that isolated.

- GL2: For example, patient who use the palliative care, is it easy for patients in your country to have palliative care in his/her home?

- Woman1 (Ireland): In Ireland, not all GPs but... because we are remote from ... We're about an hour from the hospital.

- GL2: Patient can have all... the caregivers....?

- Woman1 (Ireland): Yeah, palliative care, yeah. We have a good palliative care team I have to say, based in the hospital, it's about one hour away. We have no ambulance, we have no ...XXX... service where I live. So we're on duty all the time, 24/7. It's great

fun! ...we can't take off weekends. But the palliative care team is good in the hospital and they will send us a nurse a couple times a week, but we would manage in between times. We work very closely with the public health nurses in the area. And we would just take turns: GP, public health nurse, to go in and do the syringe driver etc, with the home care package properly in place at that stage. we can get a hospital bed; we can get all the equipment. So they can have palliative care completely at home. It's a lot of work.

- Woman 3 or Woman2 (Australia): Similar. In Australia there are also carers, in our social security system people can apply for a carers allowance. So if you have an elderly couple and one has become ill, or if you have a... a mother who has to look after a child, then the mother is actually eligible for a carers allowance which is equivalent in some respects to social security benefits for the unemployed. So there is provision for someone to take on the responsibility of looking after someone in the home, not necessarily giving medication obviously, but the care of the person can be taken on in the home, and that's subsidised. And the doctor is usually the gate-keeper for saying if this is appropriate.

- Woman2 or Woman3: That we have a very similar system to what you are talking about. The carer can get an allowance but they can also get a community care package, on top of that ...XXX... . I think it's really actually important. It makes a big difference.

COMMENTS IN GENERAL AGREEMENT

- Man2 (USA): In the US, palliative care is a MEDICARE benefit for people over age 65 that have MEDICARE, and they have fairly narrow guidelines as to who is appropriate, but many people come on to hospice and outstay their six month probability of living. ... we had one lady, it took her about 3 years to pass away, but

she was on the verge of dying every day just about. But just didn't for 3 years, but for many people, the real problem with hospice in the USA is that the average length for stay is 13 days. So people come on way late and die after a day or two and doctors tend to think: "well you know ...we can do this, we can do that intervention". They never really ask the patient and the family if they want the interventions; people just kind of expect it. What I've heard in the Canadian system it's similar: people expect to have treatment right upon until the die, and so they have nearly 70% of the people that die in hospitals. In the USA, that number is probably 35-40% who die in hospitals; the remainder will die at home. The palliative care is a good benefit in the US, and it is available even up in the little "out in the sticks" area where I am. The nurses will drive 30 miles up and see 2 or 3 patients that are on hospice, and then drive 30 miles back...

- Woman question: Will you be involved than their care airs well? (and then fully *INAUDIBLE*)

- Man2 (USA): In general, I see some of them. But I'm not involved in all of their care. Mainly because people have the habit of jumping the clinic and going to the valley for their treatment. And so we are trying to educate people to use your local clinic first and establish a "medical home" and let this be your medical home.

INAUDIBLE COMMENTS

- Man3 (UK): In UK, similar system like Ireland ...and... with very good ... this system ...that mostly if it is... dying patient, the hospice ...XXX... they set up and also there is a system called Macmillan nurse. Day to day communication with the patient do with the nurse, and nurse get guided from hospice. General practitioners unless it is,... we are mostly involved sometimes about the doses, or in an emergency, but mostly it is done by the hospice in conjunction with the Macmillan nurse. So it is pretty good system that way.

- GL2: Other?

- Man5 (Canada): We had a system of home care attendants who are not nurses, who will go and attend the patient at home for personal care, or for cleaning or cooking food, ... production some other the way. So, that works very well. We also have community care nurses, who will be able to go in and make sort of medical interventions, encourage the taking drugs for example...

- Australian doctor: ... Which country do you come from?

- Man5 (Canada): Canada! It's not all the same in Canada So I am from British Columbia on the west coast. You might find a difference on the east coast or in the middle. Hem... as far as palliative care goes; it does really revolve around the doctor. So, if the patient says that they would like to die at home, then we would make whatever arrangements we can to try make that work. And often, us going out of our way to make sure that we visit that person at home, maybe even several times a day. So it is not a solution built into the system really, it depends on the physician more to make it happen.

- GL1: Who is organizing the...the care? Is it the GP, or the family or...?

- Man5 (Canada): It really... it's sort of a combination. It is the GP requesting the services. the family can also request independently and often do. In addition, I should add that ... for mental health, there's a quite robust system of assistance. So somebody who's got problems will get visited quite frequently ...by a mental health nurse or a mental health attendant who's not a nurse. So those people are actually, I think, dealt with fairly well.

INAUDIBLE QUESTION

- Man5 (Canada): But your point about dying at home, you're absolutely right... the numbers of people that die at home in Canada, is not very high at all. It's usually in the long-term care facility or in the hospital.

- GL2: I think we have to distinguish the palliative care period and the pre-agonic care period, it is sometimes very different. They can spend lot of time in his/her home and just two days before, sometimes they are anxious and we can probably ... in France... sometimes... XXX...

Last question, in a holly world... in a wonderful land, what do you want to ... what do you expect? If you can choose what you want for rural doctors, for the patient and caregivers. What is .. in a wonderful land, what do you want?

- Man5 (Canada): One of my biggest bugbears is that people are losing the sense of responsibility for their health. So, for instance, I often think it would be much more economically viable to pay people to walk around the block once a day, than to give them drugs that they don't take. I don't know the answer of that, but I do think that people are losing the sense that 'I'm responsible for my health, and if I'm addicted to something, that is my responsibility to do something about. So, it would be one of my big wishes ... for the future, of peoples' health that they take it on as their responsibility rather than the responsibility of their GP or the hospital. Yeah, I have a question really: however, much work's been done in terms of compliance with drugs, ...hem... many drugs within ...XXX... ACE inhibitors and diuretics very commonly. It seems to me that I think you can try a blank over statins, antihypertensives or people who have got heart failure m would be on a list of 4 or 5 drugs, almost all the want to just have one pill that shoots, shoots all those things at once, then compliance is much easier.

- Man2 (USA): Someone... someone has written about that, listen. When you put a beta-blocker and a statin, and ...and aspirin in one tablet and have to take it all every day, and then you have less mortality but... you can't really do that: some people are allergic to statins, some react to some beta-blockers...

- Man5 (Canada): Yeah, I think you still have the other option , but ...XXX... a pill that had a lot of things in it ...XXX... and a lot of people could take it, it is just that we all XXX ...XXX... that this person has to be on. Anyway ...XXX... that was just a thought...XXX... .

- Man1 (Spain): Well, in Spain, in Catalonia, we are specialists in family medicine and community care. So we have like two responsibilities. But at the moment we are just family physicians it is very difficult to do things in community care. So in a wonderful life, I would like to have more time to engage with my community and to work XXX ...XXX... , work with the determinants of health, be more proactive and (not) just be reactive, and just wait for people to come to my consultation. I would like to go the community and be more proactive.

- Man3 (UK): Recently, we – in UK – there was a lecture, “Rieth lecture” by one of the prominent physicians or somebody, gives the lecture on the television and radio. So I came across somebody recently. This professor of... ...XXX... Medicine ...XXX...of Harvard University, he said that most of the deaths in the United States is due to hypertension, and his idea was that patient should be in charge of treating their own hypertension. So since then, I try, I tell my patients just buy a electronic blood pressure tablet... blood pressure instrument and control your blood C ...XXX.. and I give extra-tablets to control his blood pressure. So what do you think about that? Because I feel that this professor is right and in his statistics that patients should be in control of their own blood pressure, and it is very easy: £50 or 60€ you can get electronic blood

pressure instrument. And we give some extra-tablet, he/she can be in charge of their ... 'drive like'... what do you think about it?

- Man5 (Canada): I think you are absolutely right! I have been doing that also for many years, and I can extend that to diabetes and to a number of conditions. So, if you give the patient the tools then he starts to address what you are worrying about, not taking responsibility of himself. So I think it's an excellent idea and it should be more ubiquitous I think.

There's another thought that I had when you were speaking around guidelines... the statins have come up repeatedly and I personally think that ...you know, .. you don't need to be on a statin if you are 90. So, where is the cut-off point? [a woman: "Where is the cut-off yeah?"] There are guidelines out there. I am definitely not one for cookbook medicine and I'm not suggesting that at all. But if you have easy availability of these guidelines, I think that's a really important piece. "Guideline informed care", "evidence informed care". Everybody's going to be different; how you use that information for each patient should be different. But to have the information to start with and probably have that on your electronic medical record, easily available.... push a button and you get the guideline, or half a dozen guidelines on what you do with cardiovascular prevention. That would be very useful. We haven't got there yet in Canada, anyway.

- Man2 (USA): I think an important thing not just for rural, but for all physicians is...hem... as a society we need to lower our biases against having the death discussion. Every physician needs to get comfortable with discussing death, and we all know it's inevitable but nobody talks about it. And ...so... with patients and family: "how long you think you live, what would be a good death for you?" And...so...you

know, I am devoted to that philosophy: I want a long life, with lots of grandchildren and a good death.

- GL2: Okay! I think it is a conclusion.

GENERAL LAUGHING

Mainly, we know the patient, for education to the patient, and to think about it. Own health, I think it is the same conclusion.

Being cautious of diseases

- Man2 (USA): In China, I met a man and he is organising what he calls the 101 club. And his people that pay to belong to this club are having the philosophy: "I am going to live to be a 101". In China, that is significant because you get past the century mark and they are eating well, they having classes to train them in how to live correctly and manage their stress, they are exercising together, they have club memberships, that they go and exercise in the club with their spouses and with their children... and now ... this is a Mr Do, who is an associate with ...XXX... our hospital ...XXX... in Beijing, and ... I appreciated his philosophy, and he is an interesting man. He's put together some beautiful printed picture booklets of sights in China that the members of his 101 club should go and see. You don't have to go to Europe, you don't have to go to America; ...XXX... 'cos we've got lots of sights here in China. So he printed this book for his 101 club members. Useful thing, interesting. (*INAUDIBLE*)

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