

Chronic Pancreatitis in Primary and Hospital Based Care in Ireland: The Management of an Orphan Disease

Hazel M Ní Chonchubhair¹, Brendan O'Shea², Dara O Kavanagh³, Barbara M Ryan⁴,
Sinead N Duggan¹, Kevin C Conlon¹

Professorial Surgical Unit, Departments of ¹Surgery and ²Public Health and Primary Care, The University of
Dublin Trinity College, Tallaght Hospital, Dublin 24, Ireland

Departments of ³Surgery and ⁴Gastroenterology, Tallaght Hospital, Dublin 24, Ireland

ABSTRACT

Introduction Chronic pancreatitis is a progressive, inflammatory, malabsorptive disease of the pancreas which has significant health and socioeconomic consequences for patients. As a chronic disease, the general practitioner along with gastroenterologists and general surgeons play an integral role in the overall management of the condition, both in primary and hospital based care. The aim of this study was to conduct nationwide surveys of general practitioners and gastroenterologists/general surgeons to obtain information related to patient management, practice demographics, access to specialist services, patient numbers, awareness of guidelines, and perceptions about a potential national registry for disease surveillance. **Methods** A cross-sectional, descriptive survey. Electronic surveys were sent to gastroenterologists and general surgeons and postal surveys were sent to general practitioners working within the Republic of Ireland. **Results** The response rate for the general practitioner survey was 69% and 34% for the gastroenterologist/general surgeon survey. Majority of general practitioners (79%) and gastroenterologists/general surgeons (82.5%) reported seeing chronic pancreatitis patients in their practice. Almost all general practitioners (96%) and 69.1% of gastroenterologists/general surgeons were unaware of any national or international consensus guidelines for the management of chronic pancreatitis. **Conclusions** This study highlights the deficits in both primary and hospital based care in Ireland, and specifically emphasises that chronic pancreatitis is not being managed as a chronic disease in primary care. Moreover, this study identified a lack of guideline awareness of the existing chronic pancreatitis guidelines amongst specialists. These data provide guidance on the potential for education and training.

INTRODUCTION

Chronic pancreatitis is a chronic inflammatory, fibrotic disease, characterised by irreversible morphological change of the pancreas, and typically causes pain and / or permanent loss of function [1]. There is progressive destruction of the acinar and islet cells, formation of scar tissue, calcification and resultant deterioration of exocrine and endocrine pancreatic function. Alcohol-related pathology is the predominant aetiology worldwide, especially in Western countries. However, not all patients who abuse alcohol develop chronic pancreatitis, and one study showed that this may be as low as 3% [2]. Other aetiologies include gene mutations, hyperlipidaemia, ductal obstruction, cystic fibrosis, tropical and hypercalcaemia, while some are 'idiopathic'. The natural

history of the disease is characterised by intractable pain, malabsorption, malnutrition, periods of symptomatic flare-ups and intermittent remission, and the development of complications including type 3c diabetes and osteoporosis [3, 4].

Chronic diseases result in decreased quality of life, increased morbidity, higher mortality, and constitute a significant resource burden. In Ireland, as in other countries, chronic diseases constitute a sizeable percentage of healthcare service activity and budgetary expenditure. According to Balanda et al. [5], between 2007 and 2020 the number of chronic conditions will rise substantially and the number of adults affected will increase by approximately 40% in Ireland. For chronic pancreatitis in particular, reasons for the significant healthcare burden are many; recurrent hospitalisation, repeated primary care visits, management of exocrine/endocrine impairment, malnutrition, chronic pain treatment, management of multi-morbidities and complications. The presence of chronic, intractable pain is a particular problem, the pathophysiology of which is incompletely understood. Pain ranges from mild, sporadic episodes to intractable pain requiring regular use of opioid analgesia. Patients experience significant socioeconomic burden. Issues of concern include difficulty in maintaining employment [6],

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Correspondence Hazel M Ní Chonchubhair
The University of Dublin, Trinity College
Department of Surgery, Room 1.29
Trinity Centre for Health Sciences, Tallaght Hospital, Dublin 24
Phone +01-8964173
Fax +01-8963788
E-mail nichonh@tcd.ie

reduced quality of life [7] and lengthy hospitalisation [8]. In one study, patients reported having substantial financial complications compared to healthy controls [9]. Duggan [10], reported that a third of patients (35.5%) reported being out of work as a direct consequence of chronic pancreatitis, and just over half were in employment compared to 97% of matched controls. As a progressive disease, the aim of treatment is to minimise complications to reduce the overall impact of the disease.

The aims of this study were several fold; firstly to provide a baseline assessment of the views of clinicians on the current management of chronic pancreatitis in Ireland; secondly to identify barriers to care provision; thirdly, to obtain suggested improvements which could positively impact chronic pancreatitis management. Finally, we questioned clinicians on the prospect of a chronic pancreatitis national disease registry for disease surveillance, to investigate the general consensus of opinion amongst stakeholders of its potential use and benefit.

MATERIALS AND METHODS

Survey

Study design was a cross-sectional descriptive survey of the management of chronic pancreatitis in primary and hospital-based care in Ireland. Two surveys were purposefully designed, and both were tailored for each health professional group.

Data Collection and Response Rate

The primary care survey was piloted to a group of GPs (n=20) for content analysis, relevance and ease of use. Two repeat mailings were sent to GPs throughout Ireland. The survey pack included a prepaid stamped-addressed envelope. GPs were asked to include their practice stamp on the return mailing, for exclusion from repeat mailings.

The approximate number of GPs working in Ireland is 3,750 (Figure 1). Postal addresses were derived from the Irish Medical Directory (©IMD 2014) (which contains information on practicing doctors in Ireland) and the National Cervical Check website (which includes an online repository of registered GPs in Ireland). We extracted a 15% block randomisation purposive sample of names contained online, to equitably represent inner city, deprived, affluent, urban towns and rural areas. Of n=563 surveys sent in two mailings, 389 were returned as completed surveys, a response rate of 69%

The hospital-based survey was first piloted (n=10) to gastroenterologists and general surgeons. It was subsequently emailed to respondents included on correspondence mailing lists *via* the Irish Society of Gastroenterologists (ISG), the Royal College of Surgeons Ireland (RCSI) and email addresses included in the Irish Medical directory (©IMD 2014). The email included a link to complete the online survey *via* the electronic survey software, SurveyMonkey®.

To capture as many gastroenterologists and general surgeons practicing in Ireland, the following steps were taken (Figure 2). The survey was sent to n=164 members of the RCSI, of which n=106 were general surgeons. In addition, the survey was sent to n=345 members of the ISG, of which n=92 were gastroenterologists and n=50 were surgeons. Sixty-eight surveys were returned. Therefore, a crude estimate of response rate is 34% for surgeons and gastroenterologists.

Ethical Considerations

Ethical approval was obtained from the Joint Research Ethics Committee of St James's Hospital/Tallaght Hospital (Ref 2014/07).

Statistical Analysis

Analyses were conducted using SPSS version 22 (SPSS, Chicago, IL, USA, 2015) and thematic content analysis of qualitative information. Basic descriptive statistical analyses were performed.

RESULTS

GP Survey

In total, 389 GPs completed and returned the survey. Forty-one blank surveys were returned with practice stamps included, indicating a wish not to participate in the survey, and removal from future mailings. Two surveys were returned by *An Post* postal service due to vacant addresses.

Demographics / Practice Characteristics

Of GPs who completed the survey, 48% of practices were located in 'urban' areas and 30% classed their location as 'mixed' (rural and urban). Sixty-two percent of GP respondents were male. Most (52%) were >52 years of age, and 88% had >8 years' post-qualification experience. Most (79%) reported having chronic pancreatitis patients currently in their practice. Demographic results are detailed in Table 1.

Management of Chronic Pancreatitis /Acute Pancreatitis

Figure 3 illustrates that over a third of GP reported being 'happy to provide on-going care to patients with chronic pancreatitis'. When asked if a continuing medical education (CME) module on the primary care management of pancreatitis would be useful, 29% answered "very useful" with a minority (6.2%) selecting "of limited use" (Figure 4). Two in five (43%) GPs reported that their patients do not have access to a specially-dedicated MDT for the management of chronic pancreatitis, while 36% answered that they were unsure if there was a MDT available. Of those with MDT access, most (94%) stated that it was led by a Gastroenterologist. Almost all GPs (96%) were unaware of any national or international consensus guidelines for the management of chronic pancreatitis.

When asked about the perceived usefulness of establishing a national disease registry for chronic

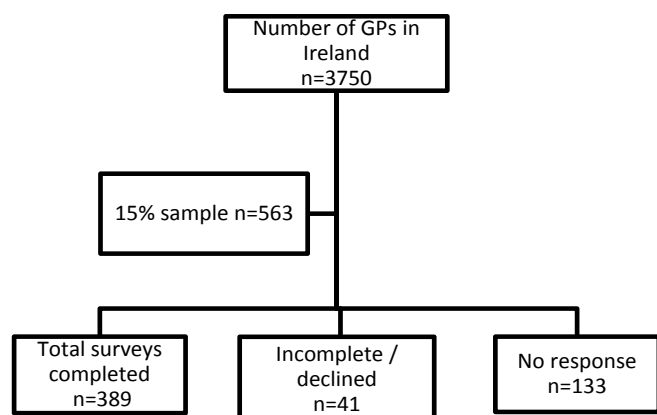


Figure 1: General Practitioner survey flow chart

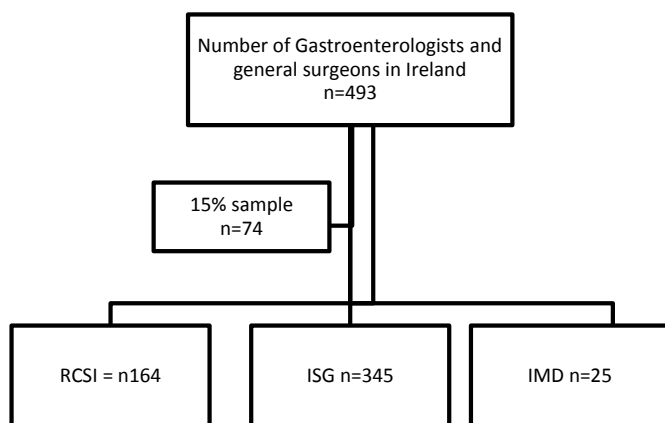


Figure 2: Gastroenterologist / surgeon survey flow chart

pancreatitis in Ireland, half of GPs (50%) reported that it would be beneficial, with 44% stating they were ‘unsure’ of its benefit. When asked if they thought that GPs would actively use such a registry, 56% reported they were ‘unsure’, while less than a third (29%) answered ‘yes’. Most (87%) GPs surveyed did not have a practice register for patients with pancreatitis. Two in five (41%) reported that they “never” code for chronic pancreatitis patients in their electronic medical record.

Table 2 summarises the responses given to the open-ended question ‘*is there any particular area of chronic pancreatitis management that you think could be improved on in the Primary Care setting*’, which were categorised according to theme. **Table 3** summarises the perceived barriers to good care for chronic pancreatitis patients in the primary care setting. Regarding acute pancreatitis management, most GPs (87%) reported seeing patients with acute pancreatitis in their practice, although 66% reported that there was no follow-up procedure in place for acute pancreatitis patients.

Gastroenterologist/General Surgeon Survey

In total, 68 surgeons/gastroenterologists completed the online surveys. Of these, 58 were usable for analysis, as 10 were incomplete.

Demographics/Practice Characteristics

Of those who completed the survey, 57.4% were surgeons. Respondents were mostly male (89.5%) and

most were either in the 34-42yr or 43-51yr age categories. Most had greater than 8 years’ experience at consultant level.

The majority of respondents worked in a university hospital (58.2%). The majority of those surveyed (82.5%) reported seeing chronic pancreatitis patients. When asked

Table 1. General practitioners demographic and practice characteristics from chronic pancreatitis in primary care survey.

GP Survey	N	%
Total surveys sent	563	
Total completed surveys	389	
Incomplete / declined participate	41	
No response	133	
Practice demographics		
Rural	85	22.1
Urban	185	48.1
Mixed	115	29.9
Gender		
Male	236	61.8
Female	146	38.2
GP age		
0-33 years	10	2.6
34-42 years	85	22
43-51 years	91	23.6
>52 years	200	51.8
Years of experience		
0-3 years	14	3.6
4-8 years	32	8.3
>8 years	341	88.1
GP trainee / registrar		
Yes	107	27.6
No	280	72.4
Undergraduate medical students		
Yes	213	55
No	174	45
Total number of CP patients currently in practice		
0	82	21.2
1-3	219	56.6
4-5	50	12.9
5-10	28	7.2
>10	8	2.1
Access to specialist multidisciplinary team (MDT)		
Yes	80	20.9
No	165	43.2
Unsure	137	35.9
Aware of CP guidelines		
Yes	15	4
No	364	96
Would a national CP registry be useful		
Yes	187	49.3
No	23	6.1
Unsure	169	44.6
Would a national CP registry be utilised		
Yes	109	28.8
No	58	15.3
Unsure	212	55.9
Do you have a pancreatitis practice register		
Yes	49	13.4
No	318	86.6

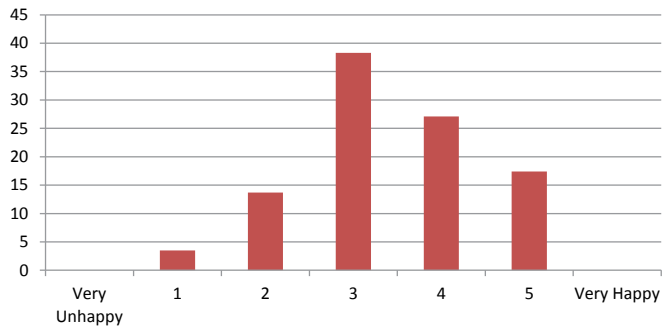


Figure 3: General practitioners survey. Scores from a 5-point Likert scale showing responses to the question; 'Are you happy to provide ongoing care to patients with chronic pancreatitis?'

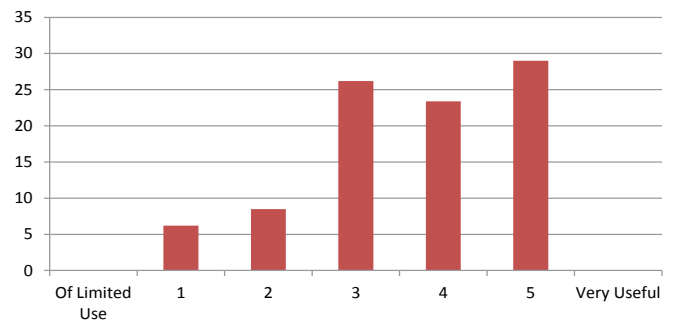


Figure 4 : General practitioner survey. Scores from a 5-point Likert scale showing responses to the question; 'How would you rate an online CME module on the primary care management of pancreatitis.'

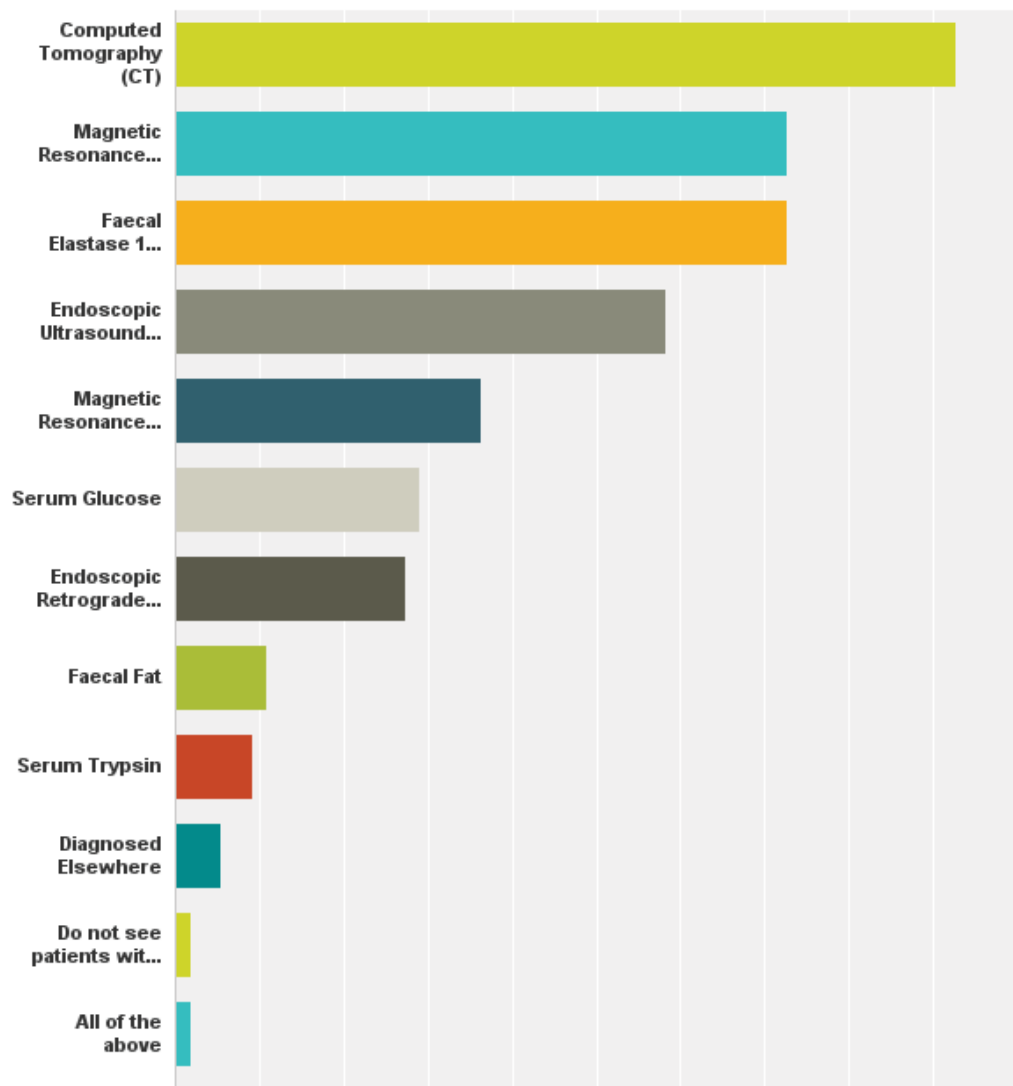


Figure 5: Gastroenterologists / general surgeons - methods of diagnosing chronic pancreatitis (More than one answer was allowed)

if their patients had access to a specially-dedicated MDT, 72.4% answered that they did not. Of those with MDT access, 94.1% were surgeon-led (Table 4).

Pancreatitis Management

Almost seven in ten (69.1%) of those surveyed were not aware of any national or international consensus guidelines for the management of chronic pancreatitis. Among those who were aware of guidelines (n=13) they specified the British Society of Gastroenterology guidelines and Italian Consensus Guidelines (Table 5).

In terms of chronic pancreatitis management and potential areas for improvements, respondents listed the following; pain control (77.6%), treatment (61.2%), nutrition (46.9%), follow-up (42.9%), biochemical diagnosis (30.6%), smoking cessation (24.5%), radiological diagnosis (22.4%) and diabetes management (20.4%). When asked if a chronic pancreatitis disease registry would be useful to estimate chronic pancreatitis prevalence, 73% of gastroenterologists and general surgeons answered 'yes', while 21.4% were 'unsure'. When asked if they thought a national chronic pancreatitis disease

Table 2. General practitioner survey. Responses to the question; ‘Is there any particular area of chronic pancreatitis management that you think could be improved on in the primary care setting?’ (More than one response was allowed).

Suggested improvements	N
Improved access to public sector health care	25
Access to a chronic pancreatitis multi-disciplinary care team	23
Access specifically to dietitian	19
Guidelines for chronic pancreatitis	19
More education	19
Pain management	11
Alcohol treatment / avoidance / addiction services	10
Treatment	9
Increase funding for chronic disease	8
Combined care plan	7
Improvements regarding diagnosis	6
Improved follow-up	4
Communication	3
All aspects of care	3

Table 3. General practitioners survey. GPs’ perceived barriers to good chronic pancreatitis management in primary care. (More than one answer allowed).

Barriers	N	%
Access to public sector services / access to specialist care / access to MDT team	54	79.4
Lack of knowledge / GP experience / education / information / guidelines	34	50
GP time / too busy	15	0.22
Poor or lack of alcohol support services	13	0.19
Poor or lack of communication between primary & tertiary care	11	0.16
Cost (of chronic care)	10	0.14
Community support services	9	0.13
Poor patient compliance with treatment	7	0.1
No dietitian available	6	0.09
Resources	6	0.09
Difficulties around diagnosis	5	0.07
Chronic disease not adequately funded	5	0.07
Priority given to more common disorders	5	0.07
Difficulties around pain management	4	0.06
No barriers	4	0.06
Demographics / deprived area	3	0.04
Follow-up	3	0.04
Analgesia dependence	2	0.03
No answer	230	59.10%

registry would be utilised by health professionals, 56% perceived that it would, with 31.4% ‘unsure’. Perceived barriers affecting the utilisation of a registry included ‘ease of data acquisition’ (50%), ease of access (46.2%), relevance to practice (40.4%), cost (38.5%), security (17.3%), confidentiality (15.4%), while 15% answered ‘all of the above’. Ninety-one percent of respondents said they treated patients with acute pancreatitis, and 65.5% of those reported having follow-up procedures in place for acute pancreatitis patients in their institutions. **Figure 5** summarises the results of the question “what investigations

do you use to make a diagnosis of chronic pancreatitis in your institution”. The majority (92.7%) used computed tomography (CT). Following this, 72.7% stated they used Magnetic Resonance Imaging (MRI) and Faecal Elastase 1 (Fe-1) in the diagnosis of chronic pancreatitis.

Table 4. Demographic and practice results from chronic pancreatitis survey sent to gastroenterologist / general surgeons.

Gastro and General Surgeon Survey results	N	%
Total surveys sent	493	
Total completed surveys	68	
Incomplete / declined participate No response	425	
Profession		
Gastroenterologist	29	42.70%
Surgeon	39	57.40%
Gender		
Male	60	89.60%
Female	7	10.50%
Age		
0-33 years	2	2.90%
34-42 years	23	34.30%
43-51 years	25	37.30%
>52 years	17	25.40%
Consultant years		
0-3 years	13	19.10%
4-8 years	19	27.90%
>8 years	36	52.90%
What type of institution		
University Hospital	39	58.20%
District / Regional Hospital	19	28.40%
Private Hospital	9	13.40%
Number of beds		
0-200	6	9.00%
201-400	29	43.30%
401-600	21	31.30%
601-800	9	13.40%
>800	2	3.00%
Access to specialist MDT		
Yes	16	27.60%
No	42	72.40%
MDT team led by		
Surgeon	16	94.10%
Gastroenterologist	1	5.90%
Intensivist	0	0
Tertiary referrals		
Yes	27	46.60%
No	29	50.00%
Unsure	2	3.40%
See CP Patients		
Yes	47	82.40%
No	10	17.50%
Aware of CP guidelines		
Yes	16	29.10%
No	39	70.90%
Would a national CP registry be useful		
Yes	41	73.20%
No	3	5.36%
Unsure	12	21.40%
Would a national CP registry be utilised		
Yes	32	56.10%
No	7	12.30%
Unsure	18	31.60%

Table 5. Gastroenterologist / general surgeon survey. National / international chronic pancreatitis management guidelines cited. (More than once response was allowed).

Guideline Name	N	%
Italian consensus guidelines	3	0.04%
BSG guidelines	3	0.04%
BMJ best practice guidelines	2	0.03%
AGA guidelines	2	0.03%
NICE guidelines	2	0.03%
GUT guidelines	1	0.01%
RCSI guidelines	1	0.01%
HPBSA guidelines	1	0.01%
ASGE guidelines	1	0.01%
Swedish guidelines	1	0.01%
Not my speciality	1	0.01%
No answer / missing	55	80.89%

AGA American Gastroenterology Guidelines; ASGE American Society of Gastrointestinal Endoscopy; BMJ British Medical Guidelines; BSG British Society of Gastroenterology; HPBSA Hepatobiliary South Africa; NICE National Institute for Health and Care Excellence; RCSI Royal College of Surgeons Ireland

DISCUSSION

This study is the first to evaluate the management of chronic pancreatitis among those directly responsible for care at both community and hospital level. It highlights the deficits in both primary and hospital based care in Ireland, and specifically emphasises that chronic pancreatitis is not being managed as a chronic disease in primary care. This is in stark contrast to the management in Ireland of other chronic diseases such as diabetes (which is only now included in the Irish General Medical Scheme (GMS) contract since 2015) and hypertension. Acute care, due to its perceived urgency, takes priority over chronic or preventative care (when services are overstretched in terms of numbers and physician time). Most Irish GPs recognise the need for significant changes in the current healthcare system to improve chronic disease management [11]. The present GMS contract makes provision for the diagnosis and acute management of illness, but makes no provision (excepting the 2015 Diabetes Care amendment) for chronic disease management in the context of current models of care for long term conditions such as the Chronic Care Model (adopted by the WHO) [12, 13] or The Patient Centred Medical Home [14, 15].

For patients with chronic pancreatitis, GPs have a major role in treating chronic pain, endocrine/ exocrine impairment, in determining the need for escalation of care and providing a vital conduit between hospital and home. Regarding hospital-based care, the complex nature of the disease means it is best-managed by a dedicated multidisciplinary team including gastroenterologists and surgeons with input from other specialities. The management principles of chronic pancreatitis include the education and reinforcement of lifestyle changes (smoking and alcohol cessation), dietary intervention, the use of pancreatic enzyme replacement therapy (PERT), and a stepwise approach to analgesia. Patients require ongoing multimodal follow-up, which should take place annually [16]. Additionally, other aspects of good chronic

care are integral, including consultation with patients regarding goals and objectives, provision of appropriate and high quality information, and confirming good care coordination, particularly during care transitions [12].

Poor guideline awareness amongst both GPs and hospital physicians is concerning. It is of great concern that we report a lack of chronic pancreatitis management guideline knowledge amongst hospital based consultants, those charged with diagnosing and planning management of these patients. To our knowledge, no other international studies have examined the awareness of chronic pancreatitis guidelines among these groups, which is also of concern. One study which surveyed Dutch gastroenterologists, internists and surgeons [17], found a wide variation in the reported use of diagnostic modalities, treatment, and screening for chronic pancreatitis. The authors pointed to a lack of evidence and consensus in the literature; however, while this may have been true in the past, there has been a considerable increase in the publication of chronic pancreatitis-specific guidelines. In the 5 years prior to undertaking this study, at least five European chronic pancreatitis management guidelines have been published [18, 19, 20, 21, 22], as well American guidelines on chronic pancreatitis diagnosis [23].

Studies examining compliance with guidelines in other conditions are markedly in contrast to that of chronic pancreatitis. In a German survey of gastroenterologists regarding the management of Crohn’s disease, an overall high adherence to guidelines was found [24]. A survey of Spanish gastroenterologists found that there was a high overall adherence to the European Crohn’s and Colitis guidelines among both specialised and general gastroenterologists [25]. The reasons for the lack of penetrance of chronic pancreatitis guidelines among Irish physicians require further investigation, and certainly, there is an urgent need for education. The development of management guidelines is costly in terms of time and resources and requires significant investment in research, assimilation, preparation and review of data. However, this process is essentially redundant unless management guidelines are used correctly by those for whom they are intended.

‘Lack of time’ was a frequently cited barrier to good management of chronic pancreatitis in primary care. The time requirements of a complex disease such as chronic pancreatitis for those providing a primary care service should not be underestimated. In a US study, the ‘top-ten’ chronic diseases were estimated to costs 828 hours per year, equivalent to 3.5 hours a day, under the premise that the disease was stable and well-controlled [26]. Notably, the ‘top-ten’ disease list discussed in the study included both diabetes and osteoporosis, both of which are complications of chronic pancreatitis.

Lack of effective communication between primary and hospital care was regularly cited by GPs as a barrier to the effective management. GPs cited inadequate coordination of care between hospitals, with a lack of direction on the

follow-up required and poor MDT access for guidance or advice. GPs also noted that as chronic pancreatitis is not formally recognised as a chronic disease, it is therefore not funded under the GMS contract (public health system).

As well as identifying the need for improved access to public sector care and MDT management, GPs identified the need for specialist dietetic intervention, pain management and alcohol/addiction services. Access to alcohol cessation supports is a crucial part of care for both primary and hospital based management. Alcohol abstinence in chronic pancreatitis may reduce pain, but more importantly slows disease progression, reduces the likelihood of complications, and prolongs life [27, 28]. When asked about the barriers to providing good chronic pancreatitis management in primary care, the lack of community resources and MDT access were again frequently cited, along with a lack (or poor awareness) of guidelines, lack of education, experience, knowledge and information. Many GPs reported interest in a learning module for chronic pancreatitis care, which could support future care efforts.

The lack of access to dietetic support is a concern as nutrition in chronic pancreatitis has previously been described as a problem area [29]. Progressive pancreatic exocrine insufficiency (PEI) leads to nutrient malabsorption, steatorrhoea, abdominal discomfort, weight loss and nutritional deficiencies [30, 31]. Early detection and effective treatment of PEI using PERT is fundamental to the nutritional management of this condition. This requires careful prescription and monitoring of function, titration and evaluation of outcomes to ensure optimal symptom control. A study from the Netherlands [32] showed that PERT is underused and under prescribed in chronic pancreatitis, and given the results of the current study, there is no reason to believe that there is better management in Ireland. Adequate PERT, analgesia, and alcohol / tobacco abstinence, along with specialist dietetic counselling are integral to the management of those with chronic pancreatitis [21]. Nutritional management should be coordinated and structured, encompassing endocrine and exocrine evaluation as well as dietary assessment, anthropometrics, biochemistry, and bone health assessment [3].

In hospital-based care, access to a dedicated MDT was also notably lacking for most respondents. Those in hospital-based care specified that strategies for pain control, treatment, nutrition and adequate follow-up were key deficits or areas for improvement for this patient group. Forsmark [27] specified that optimal management requires a MDT approach that includes gastroenterologists, surgeons, endocrinologists, dietitians, pain specialists, psychiatrists, social workers and patient support groups. However, it must be acknowledged that despite the emergence of many guidelines over the last five years [18, 19, 20, 21, 22], none specifically emphasised the importance of establishing a MDT in hospital-based care as exists within acute pancreatitis guidelines [33], nor do

any of the guidelines discuss the role of primary care in managing this disease.

Results from our study showed that the majority of gastroenterologists and surgeons (93%) use computed tomography (CT) to diagnose chronic pancreatitis. In a study [17] to evaluate decisions regarding the diagnosis, treatment and screening of chronic pancreatitis, the most common test used was faecal elastase (49.1%) and it was most often chosen by gastroenterologists (73.5%) and by experts (71.9%). We report a higher finding of 73% of those surveyed outlining the use of faecal elastase to diagnose chronic pancreatitis, with a comparable number outlining the use of MRCP (73%).

Regarding the development of a national chronic pancreatitis disease registry, while most agreed that it would be useful to estimate disease prevalence, a sizable proportion of both professional groups suggested that it would not be utilised by health professionals and that there would be considerable barriers to its effective implementation. The study highlights the diversity of value placed on the use of disease registers among specialists and GPs, which is of concern. The use of disease registers for research and for planning care and service provision is central to all models of good chronic disease management. In a survey conducted on the use of patient registries in Ireland, Donohue et al. [34] reported that many registries operated with very limited resources and a failure to employ data standards was found in some. The report also found, that for those involved in registry operation in Ireland, the lack of security of funding was a critical element, with several registries (12%) reporting no funding. There were also ethical issues about the lack of sustainable funding mechanism.

Strengths and Limitations

As with all surveys, there were important limitations of our study. We made an assumption that the respondents are representative of GPs and gastroenterologists/surgeons, however, those who chose not to reply may have more or less knowledge than the respondents, introducing an obvious bias. In addition, as the first study of this nature, we designed the survey specifically for this project. Both surveys were piloted for purpose and use, and amended where necessary. The GP survey achieved a particularly high response rate of 69%, reaching a sizeable number of Irish GPs in various settings.

CONCLUSIONS

The survey is the first of its kind internationally for chronic pancreatitis, and represents an important step in improving understanding about the management of this condition in both primary and hospital-based care. We described deficits and barriers identified by primary care physicians and gastroenterologists/surgeons regarding the management of chronic pancreatitis. Specifically, there is poor awareness of guidelines, a lack of coordinated management between primary and hospital-based care, as

well as poor access to specialist services and MDTs. Many GPs are unhappy to continue with the current levels of care, and specified a need for increased education and funding. These findings, which are applicable not only to Ireland, but to many other European Countries with comparable healthcare models, highlight a severe neglect regarding the management of patients with this progressive, debilitating chronic disease, requiring significant investment in care and education.

Contribution

HNÍc conceived and designed the study, acquired, analysed and interpreted the data and drafted and revised the manuscript. SND, BOS, DK, BMR assisted in the design of the study, the interpretation of the data and revised the manuscript for intellectual content. KCC assisted in the design of the study and the interpretation of the data, and revised the paper for important intellectual content. All named authors critically appraised the manuscript and approved the final version submitted for publication.

Conflict of interest

The authors declare that there are no conflicts of interest. The authors wish to acknowledge the financial support by means of an educational grant from Mylan Healthcare.

References

1. Sarner M, Cotton PB. Classification of pancreatitis. *Gut* 1984; 25:756-759. [PMID: 6735257]
2. Yadav D, Eigenbrodt ML, Briggs MJ, Williams DK, Wiseman EJ. Pancreatitis: prevalence and risk factors among male veterans in a detoxification program. *Pancreas* 2007; 34:390-8. [PMID: 17446836]
3. Duggan S, O'Sullivan M, Feehan S, Ridgway P, Conlon K. Nutrition treatment of deficiency and malnutrition in chronic pancreatitis: a review. *Nutr Clin Pract* 2010; 25:362-70. [PMID: 20702842]
4. Duggan SN, Smyth ND, Murphy A, Mac Naughton D, O'Keefe SJ, Conlon KC. High prevalence of osteoporosis in patients with chronic pancreatitis: a systematic review and meta-analysis. *Clin Gastroenterol Hepatol* 2014; 12:219-28. [PMID: 23856359]
5. Balanda KP, Barron S, Fahy L. Making chronic conditions count: hypertension, stroke, coronary heart disease, diabetes. A systematic approach to estimating and forecasting population prevalence on the island of Ireland. *Institute of Public Health in Ireland* 2010; 88.
6. Gardner TB, Kennedy AT, Gelrud A, Banks PA, Vege SS, Gordon SR, Lacy BE. Chronic pancreatitis and its effect on employment and health care experience: results of a prospective American multicentre study. *Pancreas* 2010; 39:498-501. [PMID: 20118821]
7. Mokrowiecka A, Pinkowski D, Malecka-Panas E, Johnson CD. Clinical, emotional and social factors associated with quality of life in chronic pancreatitis. *Pancreatol* 2010; 10:39-46. [PMID: 20332660]
8. Rutter K, Ferlitsch A, Sautner T, Püspök A, Götzinger P, Gangl A, Schindl M. Hospitalization, frequency of interventions, and quality of life after endoscopic, surgical, or conservative treatment in patients with chronic pancreatitis. *World J Surg* 2010; 34:2642-7. [PMID: 20645098]
9. Pezzilli R, Morselli-Labate AM, Fantini L, Campana D, Corinaldesi R. Assessment of the quality of life in chronic pancreatitis using Sf-12 and EORTC Qlq-C30 questionnaires. *Dig Liver Dis* 2007; 39:1077-86. [PMID: 17692582]
10. Duggan SN. Manutrition, deficiency and nutritional practice in patients with acute and chronic pancreatitis [Dissertation]. Dublin: Trinity College Dublin; 2014.
11. Darker C, Carmel M, O'Dowd T, O'Kelly F, O'Kelly M, O'Shea B. A national survey of chronic disease management in Irish general practice, I.C.G. Practitioners, Editor. 2011, Department of Public Health and Primary Care, Trinity College Dublin: Dublin.
12. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness. The chronic care model part 2. *JAMA* 2002; 288:1909-1914. [PMID: 12365965]
13. Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the chronic care model in the new millennium. *Health Aff (Millwood)* 2009; 28:75-85. [PMID: 19124857]
14. Nielsen M, Langner B, Zema C, Hacker T, Grundy P. Benefits of implementing the primary care patient-centred medical home. Washington: patient-centred primary care collaborative, 2012.
15. Reid RJ, Fishman PA, Yu O, Ross TR, Tufano JT, Soman MP, Larson EB. Patient-Centered Medical Home Demonstration: A Prospective, Quasi-Experimental, Before and After Evaluation. *Am J Manag Care* 2009; 15:71-87. [PMID: 19728768]
16. Mayerle J, Hoffmeister A, Werner J, Witt H, Lerch MM, Mössner J. Chronic pancreatitis--definition, etiology, investigation and treatment. *Dtsch Arztebl Int* 2013; 110:387-93. [PMID: 23826027]
17. van Esch AA, Ahmed Ali U, van Goor H, Bruno MJ, Drenth JP. A wide variation in diagnostic and therapeutic strategies in chronic pancreatitis: a Dutch national survey. *JOP* 2012; 13:394-401. [PMID: 22797395]
18. Frulloni L, Falconi M, Gabbriellini A, Gaia E, Graziani R, Pezzilli R, Uomo G, et al. Italian consensus guidelines for chronic pancreatitis. *Dig Liver Dis* 2010; 42 Suppl 6:S381-406. [PMID: 21078490]
19. Martínez J, Abad-González A, Aparicio JR, Aparisi L, Boadas J, Boix E, de Las Heras G, et al. The Spanish Pancreatic Club recommendations for the diagnosis and treatment of chronic pancreatitis: part 1 (diagnosis). *Pancreatol* 2013; 13:8-17. [PMID: 23395564]
20. Martínez J, Abad-González Á, Aparicio JR, Aparisi L, Boadas J, Boix E, de las Heras G, et al. [Recommendations of the Spanish Pancreatic Club on the diagnosis and treatment of chronic pancreatitis: part 2 (treatment)]. *Gastroenterol Hepatol* 2013; 36:422-36. [PMID: 23566414]
21. Delhaye M, Van Steenberghe W, Csemeli E, Pelckmans P, Putzeys V, Roeyen G, Berrevoet F, et al. Belgian consensus on chronic pancreatitis in adults and children: statements on diagnosis and nutritional, medical, and surgical treatment. *Acta Gastroenterol Belg* 2014; 77:47-65. [PMID: 24761691]
22. Takacs T, Czakó L, Dubravcsik Z, Farkas G, Hegyi P, Hritz I, Kelemen D, et al. [Chronic pancreatitis. Evidence based management guidelines of the Hungarian Pancreatic Study Group]. *Orv Hetil* 2015; 156:262-88. [PMID: 25661971]
23. Conwell DL, Lee LS, Yadav D, Longnecker DS, Miller FH, Mortele KJ, Levy MJ, et al. American pancreatic association practice guidelines in chronic pancreatitis: evidence-based report on diagnostic guidelines. *Pancreas* 2014; 43:1143-62. [PMID: 25333398]
24. Klag T, Stange EF, Wehkamp J. Management of Crohn's disease - are guidelines transferred to clinical practice? *United European Gastroenterol J* 2015; 3:371-80. [PMID: 26279846]
25. Hinojosa J, Gisbert JP, Gomollón F, López San Román A. Adherence of gastroenterologists to European Crohn's and Colitis Organisation consensus on Crohn's disease: a real-life survey in Spain. *J Crohns Colitis* 2012; 6:763-70. [PMID: 22398092]
26. Østbye T, Yarnall KS, Krause KM, Pollak KI, Gradison M, Michener JL. Is there time for management of patients with chronic diseases in primary care? *Ann Fam Med* 2005; 3:209-14. [PMID: 15928223]
27. Forsmark CE. Management of chronic pancreatitis. *Gastroenterology* 2013; 144:1282-91.e3. [PMID: 23622138]

28. Lowenfels AB, Maisonneuve P. Maisonneuve, Defining the role of smoking in chronic pancreatitis. *Clin Gastroenterol Hepatol* 2011; 9:196-7. [PMID: 21145423]
 29. Lankisch PG. Chronic pancreatitis. *Curr Opin Gastroenterol* 2007; 23:502-7. [PMID: 17762555]
 30. Duggan SN, Smyth ND, O'Sullivan M, Feehan S, Ridgway PF, Conlon KC. The prevalence of malnutrition and fat-soluble vitamin deficiencies in chronic pancreatitis. *Nutr Clin Pract* 2014; 29:348-54. [PMID: 24727205]
 31. Sikkens EC, Cahen DL, Kuipers EJ, Bruno MJ. Pancreatic enzyme replacement therapy in chronic pancreatitis. *Best Pract Res Clin Gastroenterol* 2010; 24:337-47. [PMID: 20510833]
 32. Sikkens EC, Cahen DL, van Eijck C, Kuipers EJ, Bruno MJ. Patients with exocrine insufficiency due to chronic pancreatitis are undertreated: a Dutch national survey. *Pancreatology* 2012; 12:71-3. [PMID: 22487479]
 33. Working Party of the British Society of Gastroenterology; Association of Surgeons of Great Britain and Ireland; Pancreatic Society of Great Britain and Ireland; Association of Upper GI Surgeons of Great Britain and Ireland. UK guidelines for the management of acute pancreatitis. *Gut* 2005; 54 Suppl 3:1-9. [PMID: 15831893]
 34. Donohue F. A review of patient registries in Ireland, [Dissertation]. Dublin, Ireland; Faculty of Public Health Medicine 2012.
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