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Dupuytren's disease presentation, referral pathways and resource utilisation in Europe: regional analysis of a surgeon survey and patient chart review

Editor's Choice

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SUMMARY

Aim: We explored the management of Dupuytren's disease (DD) using a surgeon survey and patient chart review. **Methods:** Twelve countries participated: Denmark, Finland, Sweden (Nordic region); Czech Republic, Hungary, Poland (East); France, Germany, the Netherlands, United Kingdom (West); Italy, Spain (Mediterranean). A random sample of orthopaedic/plastic surgeons (N = 687) with 3–30 years' experience was asked about Dupuytren's contracture procedures performed during the previous 12 months. Information $\leq$ 5 consecutive patients per surgeon was extracted from patient charts (N = 3357). **Results:** Overall, 84% of participants were orthopaedic surgeons; 56% of surgeons were hand specialists. Deciding factors for fasciectomy and dermofasciectomy were consistent across regions: metacarpophalangeal (MP) or proximal interphalangeal contracture > 45°, recurrent contracture, and high expectations for success. Deciding factors for percutaneous needle fasciotomy were less consistent across regions, but the leading factor was MP flexion < 20°. Overall, 49% of diagnoses and 55% of referrals were made by a general practitioner (GP), with regional variation: 31–77% for GP diagnoses and 36–81% for GP referrals. There were also differences in admission status (e.g. 9% of Nordic patients and 80% of Eastern patients were treated as inpatients). Most patients were treated in public hospitals and most procedures were covered by public health insurance. **Conclusions:** We found regional variations in surgical practice, patient characteristics and referral patterns. Understanding current diagnosis and treatment patterns, in relation to regional differences in health economics, may improve physicians' diagnosis of DD and guide patients towards appropriate, customised management plans.

What's known

Many published studies have described procedures for and outcomes of surgery for DC; there has been no large-scale evaluation of the disease course. Recently, the overall results from a large, two-part European study were reported. Across the region, patient preference and disease characteristics were critical factors in deciding to use a specific procedure. Fasciectomy was performed most often, and > 50% of patients had no contracture after surgery.

What's new

In the above-mentioned studies, data from 12 countries were pooled to provide a thorough overview of all variables examined. We conducted a regional analysis of the data and described region- and country-specific outcomes. Data from approximately 700 surgeons and > 3000 patients revealed interesting differences in disease presentation, referral patterns and resource utilisation. Health systems and economics are discussed as contributing factors.

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Disclosures

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Introduction

Dupuytren's disease (DD) is a fibroproliferative disorder of the palmar and digital fascia, whereby a thick collagen cord develops, causing flexion deformity of the affected metacarpophalangeal (MP) or proximal interphalangeal (PIP) joints (1–3). Genetic susceptibility to DD has been linked to multiple mutations in the Wnt-signalling pathway (4), which regulates fibroblast proliferation and differentiation in cancer and fibromatosis (5). Among patients, finger contracture is a common presenting complaint, as it can impair hand function in multiple settings (6–8). DD is more frequent in patients with type 2 diabetes than in subjects with impaired or normal glucose tolerance (9).

There is no cure for DD; however, treatment of Dupuytren's contracture (DC) usually involves surgery to remove or release the fibrotic cord. Common surgical approaches include fasciotomy, fasciectomy and dermofasciectomy. Percutaneous needle fasciotomy (PNF), a less invasive approach, is also frequently used (10,11). In Europe, treating physicians are typically orthopaedic or plastic surgeons; some are hand specialists. The type of procedure used depends on many factors, including patient age, comorbidities and disease severity (12,13).

Although there have been many small, clinic-based studies of surgical interventions for DC in Europe, there has been no large-scale evaluation of: (a) disease presentation and referral, (b) factors contributing to the selection of a specific procedure and the

outcome, (c) resource utilisation and (d) follow-up care. Recently, results from a large, two-part study, consisting of a surgeon survey and patient chart review, were published and report the overall findings for 12 participating countries in Europe (13,14). We report a regional analysis of the data to gain a better understanding of the differences in the presentation and surgical management of DD. Owing to the large amount of data, we focused on disease presentation, referral patterns and resource utilisation. In our companion article (15), we focus on procedures performed, outcomes and follow-up care.

Materials and methods

Twelve European countries were selected to represent geographical variations in Europe. Country-specific data were grouped into four regions: Nordic (Denmark, Finland, Sweden); East (Czech Republic, Hungary, Poland); West (France, Germany, the Netherlands, the United Kingdom) and Mediterranean (Italy, Spain). Orthopaedic and plastic surgeons were randomly selected to participate. Surgeons who regularly treat patients with DD in public and private practice were identified via telephone and hospital directories, Internet sites and other clinical contacts. Eligible surgeons must have had 3–30 years' experience in practicing medicine and treated more than five patients for DC from September to December 2008. They were also required to have used more than two of the following four procedures: PNF, fasciotomy (subcutaneous or open), fasciectomy or dermofasciectomy. Large numbers of physicians were screened to obtain the most relevant target population of surgeons who treat patients with DD and to account for the typically small percentage (~ 10%) of those that ultimately agree to participate.

The 15-item survey assessed types of procedures performed, waiting lists, recommended time away from work, time to conduct the procedure, outcome, follow-up care and recurrence (Surgeon Survey available online as an Appendix). One question focused on the factors that influence the surgeon's decision to use a procedure; responses ranged from 1 (strongly decreases intent) to 7 (strongly increases intent) (Table 1). Surgeons were asked to consider this list for each procedure separately and to think about patients with DC on whom they had operated during the previous 12 months. Overall mean scores were calculated for each procedure; the higher the score, the more strongly that factor influenced the decision. Details of the study design and methods are published (13).

To be included in the chart review, patients must have been diagnosed with DD and have undergone a PNF or other surgical procedures for DC by the participating surgeon from September to December 2008. There were no exclusion criteria. The 54-item questionnaire assessed patient demographics, diagnosis and referral history, procedure performed, intra- and postoperative complications, outcomes and follow-up. Details about the study design and methodology are published (14). For this report, all data were summarised using descriptive statistics; means and standard deviations are presented for continuous variables and percentages for categorical variables.

Table 1 Surgeon survey: complete list of intent factors

- Age < 45 or > 70
- Family history of DD
- Patient requires manual dexterity
- Patient request based on impairments of activities of daily living
- Patient request based on aesthetics
- MP or PIP < 20°
- MP or PIP 21–45°
- MP or PIP > 45°
- Speed of disease progression
- Patient presenting with recurrence
- Comorbidities/risk factors
- Number of fingers involved
- Anticipated long duration of postsurgical physiotherapy
- High/Moderate/Low expectations of success after procedure

Response scale:

1 Strongly decreases
2 Decreases
3 Slightly decreases
4 Neither decreases nor increases
5 Slightly increases
6 Increases
7 Strongly increases (DK [don't know] is not allowed)

DD, Dupuytren's disease; MP, metacarpophalangeal; PIP, proximal interphalangeal.

Results

Surgeon survey

Across all 12 countries, 687 surgeons were surveyed. The West region comprised the largest percentage of participating surgeons; the Nordic region contributed the smallest cohort of surgeons (Table 2). Surgeons in Denmark and Hungary had been practicing the longest; surgeons in Sweden and France had been practicing approximately 10 years less than that. Most surveyed surgeons in all regions were orthopaedic specialists; far fewer specialised in plastic surgery. A large percentage considered themselves to be hand specialists. More than half had an in-hospital practice only; however, there was wide regional variation.

Table 2 Surgeon demographics

Characteristic	Nordic (n = 61)	East (n = 130)	West n = 316)	Medit. (n = 180)	All (N = 687)
Years practicing medicine, mean ± SD	17.8 ± 8.6	17.4 ± 8.3	14.0 ± 7.5	14.6 ± 7.4	15.1 ± 7.9
Speciality, n (%)					
Orthopaedic surgeon	61 (100)	110 (85)	248 (79)	160 (89)	579 (84)
Plastic surgeon	0 (0)	20 (15)	68 (22)	20 (11)	108 (16)
Hand specialists, n (%)*	39 (64)	55 (42)	211 (67)	78 (43)	383 (56)
Type of practice, n (%)					
Hospital only	39 (64)	38 (29)	227 (72)	78 (43)	382 (56)
Mixed, but ≥ 50% hospital time	15 (25)	76 (59)	68 (22)	80 (44)	239 (35)
Mixed, but < 50% hospital time	7 (12)	16 (12)	21 (7)	22 (12)	66 (10)

*Hand surgeons were included as a subgroup of orthopaedic and plastic surgeons. SD, standard deviation.

Hospital-based practices predominated in the Nordic and West and were lowest in numbers in the East, where the inter-country variation was broad: 8% in Poland, 30% in Hungary and 50% in the Czech Republic. In the West, hospital-based practices were 10% less in the Netherlands (62%) compared with its regional counterparts (73–74%). Overall, only 10% of surgeons spent less than 50% of their time in hospital.

The top five factors contributing to the intent to use a procedure are presented in Table 3. For more invasive procedures (e.g. fasciectomy, dermofasciectomy), critical factors were highly consistent across regions: MP or PIP contracture > 45°, speed of dis-

Table 3 Top five factors* surgeons consider when making a decision to use a surgical procedure for Dupuytren's contracture

Factors	Nordic	East	West	Medit.	Total
PNF					
1. MP contracture < 20°	6.1	4.3	4.7	5.0	4.8
2. Age > 70 years	5.1	5.1	4.7	NA	4.7
3. Impairment in ADLs	NA	4.2	4.5	4.6	4.5
4. Comorbidities/risk factors	5.1	NA	4.7	NA	4.5
5. High expectations for success	5.4	4.4	4.1	4.7	4.4
Fasciotomy/aponeurotomy					
1. Impairment in ADLs	4.1	4.9	4.4	4.6	4.6
2. Age > 70 years	4.8	NA	4.6	4.5	4.5
3. Need for manual dexterity	4.3	4.6	4.4	4.6	4.5
4. High expectations for success	4.6	4.8	4.4	4.5	4.5
5. MP contracture > 45°	NA	4.5	NA	4.5	4.4
Fasciectomy/aponeurectomy					
1. PIP contracture > 45°	5.7	5.6	5.6	5.2	5.5
2. MP contracture > 45°	5.5	5.5	5.5	5.0	5.4
3. Speed of disease progression	5.1	5.7	5.3	5.1	5.3
4. Presenting with recurrence	5.5	5.6	5.4	4.9	5.3
5. High expectations for success	5.4	5.6	5.3	4.9	5.3
Dermofasciectomy					
1. Presenting with recurrence	5.8	5.0	5.3	5.0	5.3
2. PIP contracture > 45°	5.3	5.3	5.1	4.9	5.1
3. MP contracture > 45°	NA	5.0	4.7	5.0	4.8
4. Speed of disease progression	NA	5.4	4.8	4.8	4.8
5. High expectations for success	5.9	5.0	4.6	4.9	4.8

*Values are means from Likert scale with scores ranging from 1 (strongly decreases intent) to 7 (strongly increases intent). ADLs, activities of daily living; MP, metacarpophalangeal; NA, not applicable (not included in the top 5 factors for that procedure); PIP, proximal interphalangeal.

ease progression, recurrent contracture and high expectations for success. For PNF, deciding factors were more diverse and less consistent across regions. Nevertheless, the top deciding factor for PNF across all regions was MP contracture < 20°. For fasciotomy, patients' requests because of functional impairments and high expectations for success were also consistently ranked by surgeons in most regions. PIP contracture < 20°, age older than 70 years, comorbidities and patient request for aesthetic reasons were important deciding factors, but they were not consistently ranked across regions.

Overall, large numbers of surgeons had patients on a waiting list for a DC procedure; the largest percentage (82%) was for fasciectomy. Nordic surgeons had consistently more patients on a waiting list for all procedures (74–94%) compared with the other regions and overall (66–72%). However, the inter-country differences were large. In Sweden, none had patients on a waiting list for PNF or dermofasciectomy; 50% and 77% had patients on waiting lists for fasciotomy and fasciectomy respectively. By contrast, 82% of Danish surgeons and 71% of Finnish surgeons had patients on a waiting list for PNF; 100% of surveyed surgeons in both countries had patients on a waiting list for dermofasciectomy. In the West, virtually all UK surgeons (99%) had patients on a waiting list for fasciectomy; corresponding percentages for France, Germany and the Netherlands were 66%, 73% and 88%.

Overall, the mean time spent on a waiting list increased with invasiveness of the procedure, ranging from 7 weeks for PNF to 10 weeks for dermofasciectomy. Wait list times for fasciotomy and dermofasciectomy were longer in the East and Mediterranean and consistently shorter in the West. However, the wait list time for fasciectomy in the UK (11.0 weeks) was nearly twice as long as that in the Netherlands (6.6 weeks) and nearly three times as long as that in France (4.7 weeks) and Germany (4.4 weeks). For PNF, Finnish patients spent nearly three times as long on a wait list than did Danish patients (12.0 vs. 3.7 weeks). For fasciotomy, Swedish, Danish and Finnish patients spent 20.0, 7.3 and 10.1 weeks on a waiting list respectively. For fasciectomy, Swedish and Finnish patients spent more than twice the time on a wait list than did Danish patients (15.0 vs. 6.7 weeks).

Patient chart review

About 90% of all patients (N = 3357) were aged 50 years or older. Although Nordic patients represented the oldest cohort, and Swedish patients were the oldest in the region, the intraregional variation was large (standard deviation (9) ~ 10 years). The majority of patients were men. Far fewer patients in the Nordic region had risk factors for DD (e.g. type 2 diabetes, drinking alcohol, smoking); however, Nordic patients had more severe disease at diagnosis, more family history of DD, and more personal history with DC. About 50% of patients had contractures > 45° (Tubiana stages II–IV) at diagnosis with the exception of Nordic patients, with nearly 70% having contractures of this severity. Mean number of affected fingers and joints was consistent across regions (Table 4). For most patients in all regions, only one hand was affected and, among those, the right hand was affected more often than was the left (57% vs. 31%).

Overall, the mean duration from the date of DD diagnosis to the date of surgery was 30 months. This time period was shortest in the East and longest in the West; however, the intraregional variation was large. Most of this time (80%) can be accounted for by the long delay from DD diagnosis to referral (24 months), for which there was also inter-regional variation. Mean time from referral to surgery was shorter (6 months) (Figure 1). In the West, the long duration from diagnosis to referral can be attributed to delays of approximately 3 years in Germany and the UK. Similarly, delays in Finland and Hungary were notably shorter vs. their regional counterparts (Figure 2).

Most DD diagnoses were made by general practitioners [(GPs); 49%], followed by the participating surgeon (22%) or another orthopaedic surgeon (13%). This ranking was consistent across all regions; however, the proportion of DD diagnoses made by GPs was notably higher in the Nordic and West and notably lower in the East and Mediterranean. Within each region, there was considerable inter-country variation. In the Nordic region, the percentage of DD diagnoses made by GPs was notably lower in Sweden than in Denmark and Finland. In the West, the rate in Germany was lower compared with its regional counterparts. In the East and Mediterranean regions, where GP diagnosis of DD was less common overall, rates in Hungary and Italy were lower still (Figure 3).

The most frequent sign/symptom used to make the DD diagnosis was finger flexion towards the palm (75%), followed by patient complaints about function (57%) and the presence of a lump on the palm or finger (51%). Only 36% of diagnoses were based on a positive table-top test. In the East, finger flexion and complaints about function were used equally (70% and 69% respectively); a higher percentage of diagnosing physicians in the East also used patient complaint about appearance (41% vs. 28% overall). In the Mediterranean region, a higher percentage of diagnosing physicians also used patient complaints about pain (28% vs. 17% overall).

Table 4 Summary of patient demographic and clinical characteristics

Patient characteristic	Nordic (n = 274)	East (n = 650)	West (n = 1532)	Medit. (n = 901)	All (N = 3357)
Age, years, mean ± SD	64.5 ± 10.8	61.2 ± 9.9	62.3 ± 10.4	60.9 ± 9.6	61.9 ± 10.2
Age cohort, n (%)					
< 50	26 (10)	71 (11)	168 (11)	105 (12)	370 (11)
50–65	122 (45)	368 (57)	762 (50)	505 (56)	1757 (52)
≥ 66	125 (46)	211 (33)	602 (39)	291 (32)	1229 (37)
Male gender, n (%)	235 (86)	521 (80)	1214 (79)	764 (85)	2734 (81)
Comorbidities, n (%)					
Type 1 diabetes	14 (5)	41 (6)	114 (7)	91 (10)	260 (8)
Type 2 diabetes	32 (12)	130 (20)	285 (19)	216 (24)	663 (20)
Drinks > 3 alcoholic beverages/day	6 (2)	103 (16)	272 (18)	197 (22)	578 (17)
Smokes > 5 cigarettes/day	49 (18)	299 (46)	623 (41)	441 (49)	1412 (42)
Family history of DD	80 (29)	133 (21)	397 (26)	134 (15)	744 (22)
Previous history of DC	54 (20)	36 (6)	176 (12)	54 (6)	320 (10)
Hands affected, n (%)					
Only one hand	238 (87)	567 (87)	1320 (86)	826 (92)	2951 (88)
Only right hand	134 (49)	378 (58)	816 (53)	599 (67)	1927 (57)
Only left hand	104 (38)	189 (29)	504 (33)	227 (25)	1024 (31)
Both hands	36 (13)	83 (13)	212 (14)	75 (8)	406 (12)
Severity at diagnosis (bilateral), n (%)					
Nodules	5 (2)	17 (3)	82 (5)	51 (6)	155 (5)
Ia (< 20°)	19 (7)	99 (15)	180 (12)	131 (15)	429 (13)
Ib (20–45°)	62 (23)	213 (33)	488 (32)	254 (28)	1017 (30)
II (45–90°)	119 (43)	192 (30)	468 (31)	287 (32)	1066 (32)
III (90–135°)	56 (20)	97 (15)	218 (14)	131 (15)	502 (15)
IV (> 135°)	13 (5)	29 (5)	70 (5)	43 (5)	155 (5)
Fingers affected, mean ± SD	1.7 ± 0.9	2.2 ± 1.0	2.0 ± 1.1	1.9 ± 1.0	2.0 ± 1.1
Fingers affected, n (%)					
1	140 (51)	161 (25)	616 (40)	363 (40)	1280 (38)
2	95 (35)	314 (48)	596 (39)	376 (42)	1381 (41)
≥ 3	39 (14)	175 (27)	320 (21)	162 (18)	696 (21)
Joints affected, mean ± SD	2.5 ± 1.6	3.6 ± 2.2	2.8 ± 2.4	2.8 ± 2.1	3.0 ± 2.2
Joints affected, n (%)					
MP joint	218 (80)	551 (85)	1281 (84)	706 (78)	2756 (82)
PIP joint	217 (79)	507 (78)	1056 (69)	629 (70)	2409 (72)
DIP joint	34 (12)	202 (31)	257 (17)	244 (27)	737 (22)
Healthcare coverage*					
Public insurance	253 (92)	642 (99)	1364 (89)	762 (85)	3021 (90)
Private insurance	10 (4)	1 (0.2)	367 (24)	114 (13)	492 (15)
No insurance/unknown	11 (4)	7 (1)	43 (3)	27 (3)	88 (3)
Location of procedure, n (%)					
Public hospital	225 (82)	540 (83)	1279 (84)	749 (83)	2793 (83)
Private hospital	49 (18)	110 (17)	253 (17)	152 (17)	564 (17)

*Percentages may not add up to 100% because some patients were covered by public and private health insurance. DC, Dupuytren's contracture; DD, Dupuytren's disease; DIP, distal interphalangeal; MP, metacarpophalangeal; PIP, proximal interphalangeal; SD, standard deviation.

More than half of the referrals to the participating surgeon came from GPs, followed by the participating surgeon (i.e. self-referral) or another orthopaedic surgeon. Again, this ranking was consistent across all regions; however, GP referrals were notably higher in the Nordic and West regions (Figure 4) vs. overall. In the Nordic region, GP referrals were higher in Denmark and Finland compared with Sweden (Figure 5). In the West, GP referrals were highest in the UK and lowest in Germany. In the East and Mediterranean regions, GP referrals were lower vs. overall. Self-referrals were highest in the Mediterranean region; Italy was the only country for which there were a larger number of self-referrals than for GP referrals.

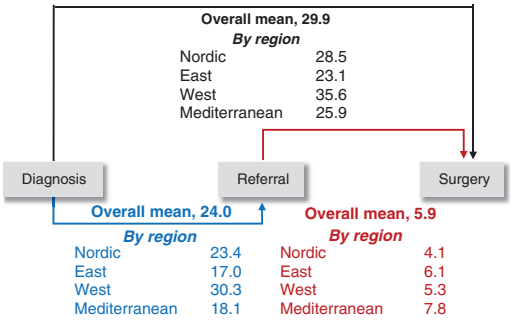

Figure 1 Mean duration (months) between steps for management of patients with DC

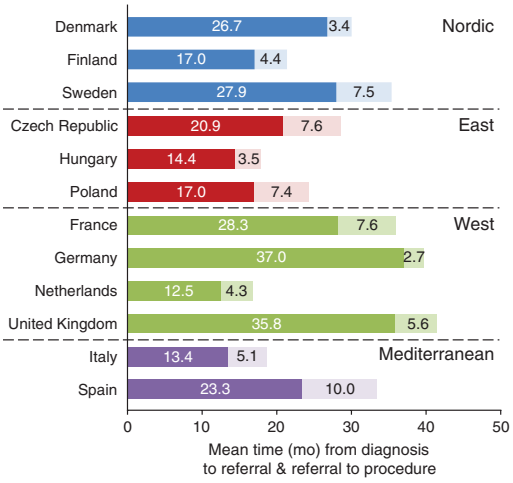

Figure 2 Time from diagnosis to referral (dark bars) and from referral to procedure (light bars) by region and country

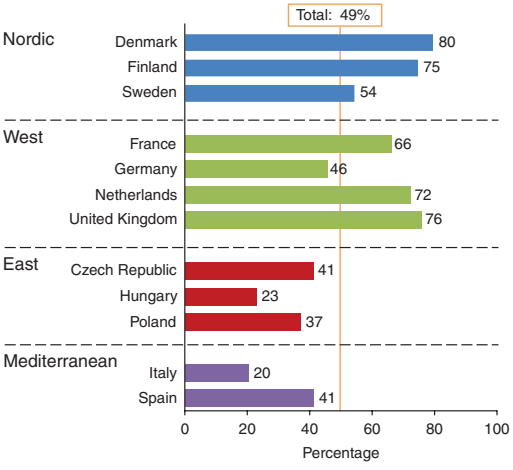

Figure 3 GPs performing initial DD diagnosis by region and country

DC procedures for the vast majority of patients in all regions were covered by public health insurance (Table 4). In the East, public sources covered

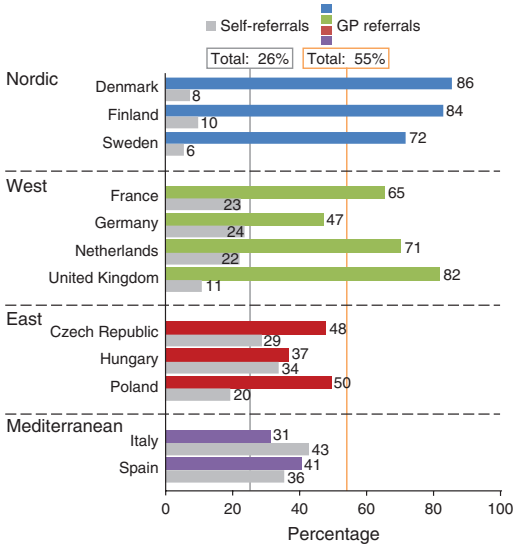

Figure 4 GP and self-referrals* to treating surgeon by region and country. *Values for each country may not sum to 100% as there were other sources of referrals not shown in the figure

virtually all procedural costs. In the Nordic region, private insurance paid for small percentages of expenses; in Finland, about 10% of procedures were paid by the patient. Multiple sources of coverage were typical in the West. In France, 97% of procedures were covered by public insurance, and 53% were covered, at least in part, by private insurance. In Germany, 81% of procedures were covered by public insurance and 19% by private insurance. In the Netherlands, the corresponding values were 69% and 20%. In the Mediterranean region, virtually all DC procedures were covered by public insurance in Italy (94%); in Spain, 75% were covered by public insurance and 23% by private sources.

For the majority of patients in all regions, the procedure for DC was performed in a public hospital (Table 4) and, among these, there were marked regional differences in patient admission status. In the East, 80% of patients were admitted as inpatients; in the Nordic region, only 9% were admitted as such (Figure 6). Within regions, there were some inter-country variations. In the West, only 9% of patients in the Netherlands were admitted to hospital compared with its regional counterparts (Figure 7). In the East, virtually all patients were admitted to Hungarian hospitals (96%); in the Czech Republic, this percentage was notably lower (58%). Among inpatients, the mean ± SD length of stay (LOS) was 2.3 ± 1.6 nights. In the East, LOS was the longest (2.9 ± 1.6 nights) and nearly two-third of inpatients stayed 2-3 nights. The LOS was shortest in the Nordic region (1.2 ± 0.6 nights), and 88% of inpa-

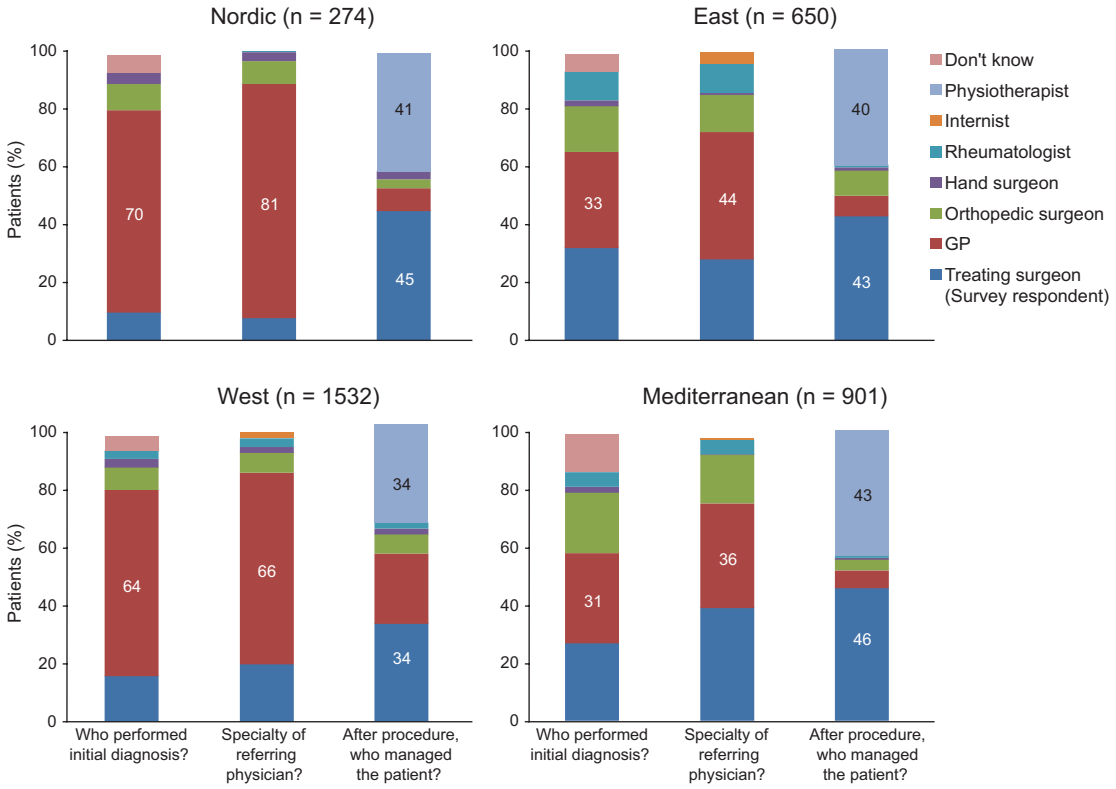

Figure 5 Referral pathways by region. *The data are not contingent categories; sample size for each of the three questions was the same per region

tients stayed in hospital for one night. For out-of-hospital procedures, there were marked inter-country differences that are not inherently obvious when looking at the regional averages.

Discussion

This two-part study was expansive in terms of geography and comprehensive in terms of content. Twelve European countries participated, nearly 700 surgeons were surveyed, and more than 3350 patient charts were reviewed. The data amassed are considerable, and the information should be of great value to researchers, clinicians, patients and the public. To date, however, only overall findings from the surgeon survey (13) and patient chart review (14) have been published. Here, we provide an in-depth assessment of region- and country-specific data to gain a better understanding of patterns of disease presentation and diagnosis, patient demographics and resource utilisation.

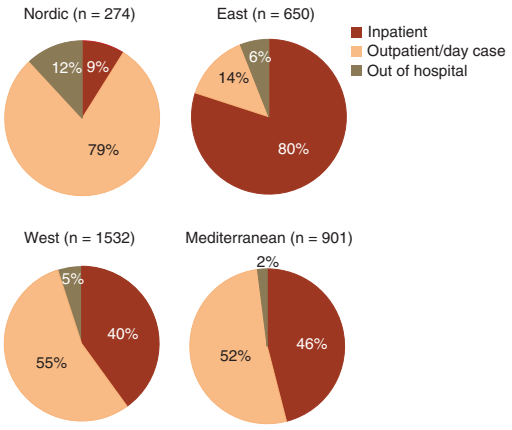

Figure 6 Patient status for DC procedure by region

Survey results suggested that there was little regional variation in surgical experience or specialty; all participants had been practicing medicine for 14–18 years and most were orthopaedic surgeons. Many considered themselves to be hand specialists, but there was no formal verification of this as part of the study. To date, there is no European consensus for the formal verification of hand specialist status. The results are consistent with those from a retrospective database analysis of Hospital Episodes Statistics in England (16). During a 5-year period (2003–2008), 79% and 19% of DC admissions were overseen by orthopaedic and plastic surgeons respectively. These percentages varied little from year to year (16).

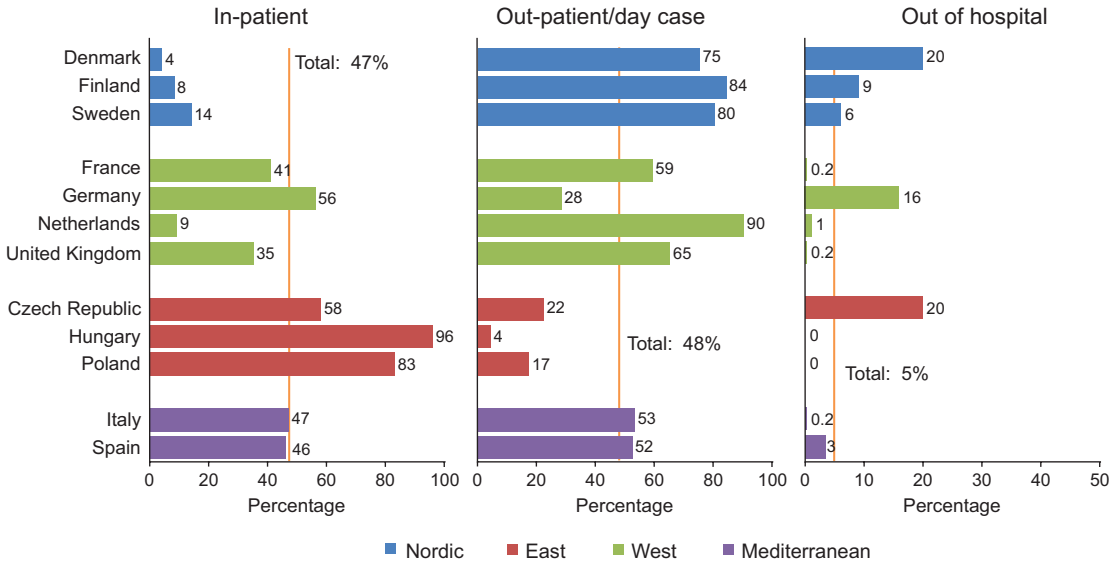

Figure 7 Patient status for DC procedure by region and country

When deciding what type of procedure to perform, the degree of contracture was the most important contributing factor. For patients with severe and/or rapidly progressing disease, a more invasive procedure (fasciectomy, dermofasciectomy) was preferred. This is consistent with the literature (12,17) and, as an example, Armstrong noted, 'It is not our practice to use a single procedure for all patients with [DD] but to match the surgical intervention to the nature of the disease' (18). One author (LBD) usually describes the advantages and disadvantages of each procedure to the patient; the ultimate decision is typically mutually agreed and based on surgeon expertise and patient preference.

In all regions, most surgeons had patients on a waiting list for surgery, and there was some regional variation, likely owing to differences in available resources. Nevertheless, most participating countries have changed their provision of care guidelines in an effort to reduce wait list times. In Sweden, a maximum waiting-time guarantee was introduced in 2005 and was based on the '0–7–90–90' rule. That is, a patient should be able to: have immediate contact with the healthcare system, see a GP within 7 days, consult with a specialist within 90 days and receive treatment within 90 days of diagnosis (19). Our results showed that, at least for the orthopaedics specialty, some wait list times in Sweden were higher than those in its Nordic counterparts and overall. This finding is corroborated in a Health Systems report on Sweden, where the longest waiting lists were in the orthopaedics and plastic surgery clinics (19). In addition, with few exceptions, DD is a slowly progressive disorder, and immediate treatment is rarely necessary. Thus, even when contracture is severe enough to affect hand function, it may not be serious enough to impair work- and/or household-related activities. Patients usually cope with or adapt to the disability. Furthermore, many patients with DD are retired, so sick leave is not a factor while waiting for surgery.

In Nordic countries, particularly Sweden, most patients are selected for a partial fasciectomy, which usually includes skin cover with Z-plasty or even split-skin or full-thickness graft. In general, patients who receive PNF do so because of the surgeon's preference for this method, and the technique has grown in popularity in recent years (20). A simple fasciotomy is traditionally used less frequently, as supported by the current findings. Moreover, in clinical practice, co-morbidity is an important factor in the decision to use a particular treatment strategy. For example, patients with type 1 or type 2 diabetes, who are at greater risk for DD than are those with impaired or normal glucose tolerance, rarely undergo surgery for DC (9).

The patient chart review revealed interesting inter-regional differences as well as some intraregional, country-specific patterns. For example, although patients in the Nordic region had fewer comorbidities and risk factors, disease severity was greater vs. other regions. This is likely due – at least in part – to the known lineage of DD from Northern Europe (21,22). The fact that Nordic patients had more personal and family history with DC is consistent with the literature, although patient-reported information of this nature is typically unreliable owing to recall bias, among other things.

There was marked inter- and intraregional differences in the duration from DD diagnosis to referral

and from referral to surgery. The former delay was surprisingly long overall (30 months), ranging from 1 year in the Netherlands to 3 years in Germany. However, chart review findings also showed little change in contracture severity from the date of DD diagnosis to the date of surgery. Therefore, it may be that GPs had managed patients with 'watchful waiting,' as DD is slowly progressive in most patients. Nevertheless, other research has shown that surgical intervention at earlier stages of contracture leads to better outcomes (23). However, the high risk for recurrence has to be considered in decision-making for treatment. Overall, there was a 6-month delay from referral to surgery, ranging from 3 months in Germany to 10 months in Spain. This may be due more to wait lists and resourcing than to disease characteristics (see below).

About half of all DD diagnoses and referrals were made by GPs. Higher rates in the Nordic and West regions and lower rates in the East and Mediterranean regions may be related to different healthcare systems and policies related to the provision of care. The GP diagnoses and referrals were highest in Denmark, which is expected given that the default coverage system requires GP diagnosis and specialty referral (24). The rates in Finland were also high and likely because of the country's mandatory resident registration at municipal health centres and assignment to a GP (25). In Sweden, where GP diagnoses and referrals were lowest for the region, residents can opt to see a GP for a first visit or contact a specialist directly (19). Indeed, initial monitoring by a GP may be more efficient provided that the physician is meticulous in detailing the patient's progress and eventual indications for surgery. Thus, a patient can be referred to a specialist at a more appropriate time, again provided there is no waiting list for surgery. In the East and Mediterranean regions, GP diagnoses and referrals were lowest overall. In Hungary, where GP diagnosis rate was the lowest for the region, the policy of using the GP as a 'gate-keeper' has not been effective (26). One reason may be the low physician-to-population ratio. In one report, Hungary was second only to Poland in the fewest number of physicians per 100,000 population (309 and 216 respectively) (24). However, for Italy, which also had one of the lowest rates of GP diagnosis and referral, physician per 100,000 was 412 in 2008, the highest among countries in the World Health Organisation European Region (24). Italy was the only country that had a higher self vs. GP referral rate.

Finger flexion towards the palm and functional impairment were most often used to diagnose DD. Only one-third of diagnosing physicians used the table-top test as part of their work-up, which is also consistent with the literature (12). Only a small number of physicians use this quick, easy and definitive test for DD first described by Hueston. Also of interest is the seemingly large percentage of physicians who used the patient's complaint about pain in making a diagnosis of DD. This is in light of the fact that pain is not a common presenting symptom among DD patients (27); however, pain may become more prevalent as nodules or contractures develop. In a study on factors contributing to joint complaints, there was no difference between patients with or without DD and the degree of pain associated with their joint problems (28). In a psychometric evaluation of a DD-specific questionnaire, pain was not a factor that was associated with or linked to the physical impairment caused by DD (29).

There were also interesting inter-regional and inter-country differences in patient admission status and insurance coverage for DC procedures, which may be because of differences in the country-specific systems under which these services were provided. In the Netherlands, where inpatient admissions were quite low, the percentage of 1-day admissions doubled in the past 10 years and surgical procedures are more often performed in the day-case setting (30). In Hungary, nearly all DC procedures are performed on an inpatient basis. In one report, the inpatient specialist care sector was awarded 77% more EU-funding than the outpatient care sector (26). Furthermore, the number of surgical interventions eligible to be performed on a day-case basis expanded from 13 in the mid 1990s to 340 by the end of 2010 (26). In all of the participating countries, the majority of patients were covered by public health insurance. The only outlier, France, had more than half of its patients also covered by private insurance. Recently, a reversal in surgical venue has been reported from UK, where inpatient operations decreased as day-case procedures increased. This is consistent with a recent report that although the country has universal Statutory Health Insurance (public), 88% of the French population has Complementary Health Insurance (private) (31). It was interpreted, and most likely, that such a change is the result of economic trends and changes in the healthcare systems in Europe (16).

This large, European surgeon survey and patient chart review produced a rich set of data; however, there are limitations on their interpretation based on the study design and temporal changes in the countries evaluated. First, the results are reported and interpreted descriptively, not inferentially. Thus, the findings can only serve to generate hypotheses and to help define research objectives in the design of future studies. The survey is prone to recall bias, as the

surgeons were asked to recall patients they treated during a 12-month period. Similarly, for the patient chart review, the quality of the results is largely dependent on the quality of the data extracted from medical records. Furthermore, some information contained therein, such as patient-reported drinking and smoking habits, is not as reliable as that collected during a physical exam or objective testing.

In conclusion, data from hundreds of surgeons and thousands of patients in Europe were used to characterise the management of DD, including surgical practice, patient characteristics and referral patterns. Understanding current diagnosis and treatment patterns and their potential relationships to country-specific health systems and economics may improve physicians' recognition and diagnosis of DD and guide patients towards an appropriate, customised management plan.

Author contributions

C Bainbridge, JC Cappelleri, J Dias, LB Dahlin, RA Gerber, D Guerin and C Leclercq were responsible for the concept and design of the manuscript. D Guerin collected the data. JC Cappelleri, LB Dahlin, J Dias, RA Gerber, D Guerin and PP Szczypa analysed and interpreted the data. C Bainbridge, JC Cappelleri, LB Dahlin, J Dias, RA Gerber, D Guerin, C Leclercq and PP Szczypa drafted, critically revised and approved the final manuscript.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Surgeon Survey Questionnaire.

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