International Patient Survey (Part 1: Dupuytren Disease)

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5.1 Introduction

The advent of new, additional treatments for Dupuytren Disease offers more options but also requires more information for choosing the right one. For counseling, physicians need to understand strengths and weaknesses of *all* available therapies and the preferences of patients, individual, and in general. Physicians have already been surveyed across Europe and elsewhere how they are treating Dupuytren Disease and what side effects they are observing (Dahlin et al. 2013; Dias et al. 2013). The aim of this survey is getting more insight into aspects of counseling by physicians, such as completeness of information about the various treatment options and satisfaction of patients with the treatment provided. The authors hope that results of this survey will help to improve understanding of what aspects of counseling are important for patients and will encourage additional studies to further improve treatments. Ultimately it is the patient who decides how beneficial and successful a treatment is.

Part 2 of this survey addressing Ledderhose Disease is presented in Part 9 of this book (Schurer et al. 2016).

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5.2 Materials and Methods

5.2.1 Concept and Goals of the Survey

To reach as many patients as possible, the survey used a simple online questionnaire. The questionnaire was in English, except for Germany and Austria, where an in German translated version was used. Patients started the survey through a SurveyMonkey website. Questions were intended to be easy to understand, without further explanations, and filling out the survey should be possible in 5 min (verified by the authors prior to the survey and confirmed by tracked response times: about 25 % of the respondents took less than 5 min to fill out the survey).

The survey had four sections, the first one covered 12 general questions (e.g., age, gender, family history, other diseases, lifestyle, country), the second one addressed Ledderhose Disease, the third section asked questions about Dupuytren Disease (e.g., how long have you been suffering from it, what treatments did you receive, how do you rate the effectiveness of the received treatment), and the last section asked to rank the experience of the medical community and had two open-ended questions ("Do you feel there is anything that needs to be improved with regard to counseling, available information, treatment options, rehab, research, etc.?" and "Is there any relevant information you would like to provide?"). Patient could choose which questions were applicable for them and responded to those only.

Overall the survey addressed:

- Quality of treatments
- Quality of counseling
- Effect of lifestyle (smoking, drinking)
- Related diseases
- Country-specific differences, if existing
- Needs of patients (open-ended questions).

A few of the questions were redundant to allow checking validity, e.g. it was asked "how old are you", "when did your disease start", and "how long have you been suffering".

The data were collected without patient identification, i.e., without name, address, or email address. Only IP address, country, age, gender, and time of data entry were recorded. Everybody could participate; a clinical diagnosis was not required (being often inconsistent anyway; Anthony et al. 2008), but we presumed that treated patients were properly diagnosed before treatment.

5.2.2 Participating Organizations

The survey was initiated by Gary Manley's Ledderhose Disease blog and then extended to include Dupuytren Disease. Supporting organizations were:

- The Ledderhose Disease blog
- The International Dupuytren Society
- The British Dupuytren's Society
- The German Dupuytren Society (Deutsche Dupuytren-Gesellschaft)
- The Dupuytren Foundation.

Patients were invited to participate in the survey via websites, forums, and mailing lists. In Germany some clinics additionally encouraged their patients to participate. We estimate that *all* together about 10,000 patients were invited. It was not a requirement that patients had been treated already, i.e., the survey includes also patients in the early stage of disease, which is different to most studies researching patients from hospitals or clinics exclusively.

5.2.3 Data Correction

Patients participated in the survey without having to register. We had no protection against misuse, but did not find any indication of misuse either. One problem with not having to register was that patients could fill out the survey more than once. Occasionally and obviously a patient wanting to correct a wrong input started again from scratch instead of going back to the previous page or question. Typically these records were close to each other (similar or subsequent session ID),

used the same IP address, and were identical except very few entries, and the first record was typically only partially filled. In those cases the first record was deleted from the survey (31 records deleted).

The difference between "age" and "In years how long have you had Dupuytren's?" gives the age of onset, which was additionally inquired by "At what age did you first start showing symptoms of Dupuytren's?." If those values differed, the record was inspected. A typical mistake was, e.g., entering something like "2004" as age of onset. This was corrected.

5.2.4 Statistics

Data were stored as spreadsheets; for analysis the English and German spreadsheets were merged into one. Evaluation was by conditioned spreadsheet functions, like AVERAGEIFS. The Kruskal–Wallis test was applied for analyzing the effect of drinking and the Mann–Whitney U test for analyzing the effect of smoking, both by using SPSS.

5.3 Results

Data collection started in July 2014. The survey is still ongoing (http://www.dupuytren-online.info/Forum_English/, accessed September 2015), but the results presented here are based on the data collected until the end of March 2015. The total number of responses for Dupuytren Disease at that time was 2,235; 1,310 male and 925 female patients participated (ratio of 1.4:1). The average age was 59 for both genders. Including patients who suffered from Ledderhose Disease only, the overall response rate of the survey was about 25 %.

Due to the two languages used, participants were mainly from the USA, the UK, and Germany (Fig. 5.1). Larger contributions came also from Canada (94) and Australia (90). Patients did not have to answer *all* questions; therefore for most questions, the number N of responses is less than the total number.

5.3.1 Gender-Dependent Age of Onset

The average age of onset of Dupuytren Disease of *all* patients was 47.7 (median = 49). Figure 5.2 shows the age of onset by age groups and could be interpreted that for men, Dupuytren Disease starts about 10 years earlier than for women (Ross 1999). But that is an artifact caused by the specific age grouping. According to our data, men develop this disease on an average at the age of 46 and women at an age of 50.1, i.e., only 4 years later ($p < 0.001$). Note that earlier onset for men appears even in the lowest age group,

Europe:

Country	DD patients
Austria	15
Belgium	5
Denmark	4
France	14
Germany	**399**
Holland	23
Ireland	28
Norway	3
UK	**367**
Other Europe	38

Fig. 5.1 Geographical distribution of participants with Dupuytren Disease

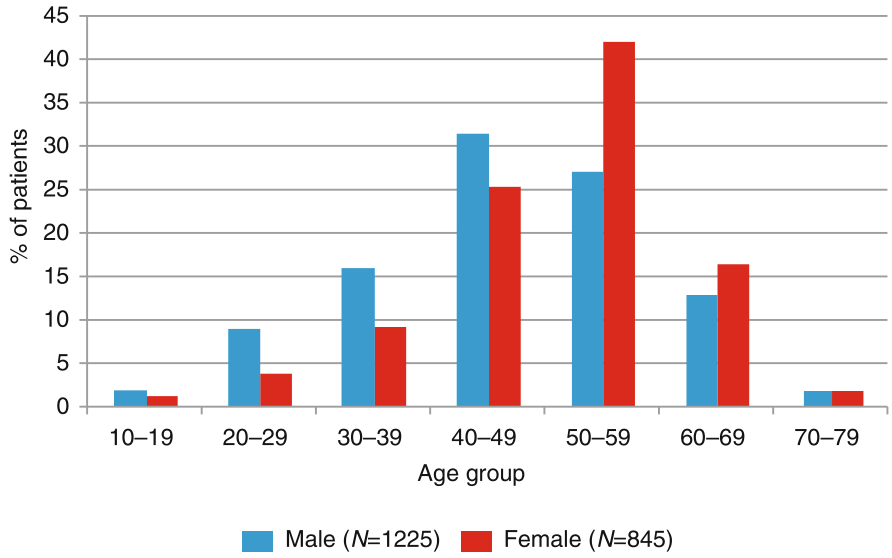

Fig. 5.2 Gender-dependent age of onset of Dupuytren Disease

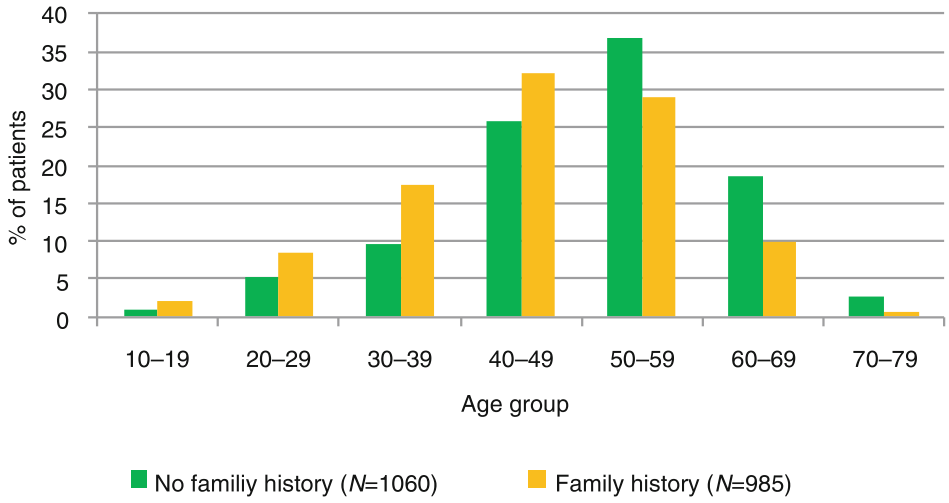

Fig. 5.3 Age of onset with and without family history

where work or lifestyle has no effect yet. Although in that age group statistical significance is low (male $N=21$, 1.7 %; female $N=10$, 1.2 %), it might still indicate genetic causes.

5.3.2 Family History

Family history is also affecting the age of onset. Figure 5.3 shows the data for *all* participants, excluding patients who were not sure.

On average our patients with confirmed family history report an onset of Dupuytren Disease at 44.9 years (median = 45), while those without family history have an average age of onset of 50.3 years (median = 51). For men with family history, we find 42.8 years and 49.4 years without ($p<0.001$), for women 44.9 and 50.3 years, respectively ($p=0.003$).

5.3.3 Lifestyle

To explore the effect of drinking alcohol and smoking, patients were asked whether they were currently smoking or not (smoking: male = 11 %; female = 9 % with higher percentages in Europe and lower in the USA) and whether they were

drinking less than 2 glasses of wine/pints of beer per day, more than 2 glasses or not drink at *all*. We did not inquire about previous habits (Table 5.1)

Figure 5.4a shows the effect of smoking on the age of onset for *all* patients. Figure 5.4b excludes other influences causing an earlier onset, like male gender or family history.

Smoking seems to cause an earlier onset. The effect is most obvious in the age group 30–39 ($N=50$ smoking, 224 not smoking for *all* patients), where people already have smoked for a longer period of time. It seems to take a while until the effect builds up because it is still smaller in the age group 20–29. The effect is similar for both genders: in the age group 30–39 smokers develop Dupuytren Disease twice as often as nonsmokers: 32.4 % of male smokers vs. 16.1 % of male nonsmokers and 20.5 % of female smokers vs. 9 % of the female nonsmokers.

According to our results (Table 5.2; patients with age of onset < 15 are excluded), smoking men develop Dupuytren Disease 7 years earlier if they have no family history, and only 3 years earlier with family history, but unfortunately results for smokers are lacking statistical significance. You have to start with large numbers for such an analysis. Interestingly, for smoking + family history, the age of onset is about 9–10 years earlier for both, men and women.

Different to smoking we did not observe a negative effect of the drinking behavior on the onset of Dupuytren Disease (Table 5.3); *p*-values are varying between 0.12 and 0.77.

Table 5.1 Daily drinking habits of the participants

	Male	%	Female	%	Total	%
I do not drink	252	19.2	325	35.1	577	25.8
Less than 2 glasses	685	52.3	499	54.0	1184	53.0
More than 2 glasses	373	28.5	101	10.9	474	21.2

Table 5.2 Effect of family history, smoking, and gender on the age of onset

Family history	Yes	*N*	No	*N*	*p*-value
Male not smoking	43.5	521	50.4	345	*0.001*
Male smoking	40.7	47	43.3	52	0.838
Female not smoking	48.5	382	53.0	192	*0.001*
Female smoking	43.9	28	45.7	23	0.588

Table 5.3 Effect of alcohol, smoking, and gender on the age of onset

Alcohol	>2 glasses	<2 glasses	Not drinking
Male not smoking	47.9	45.8	45.9
Male smoking	42.6	43.4	39.6
Female not smoking	50.8	50.1	51.0
Female smoking	49.5	44.5	47.0

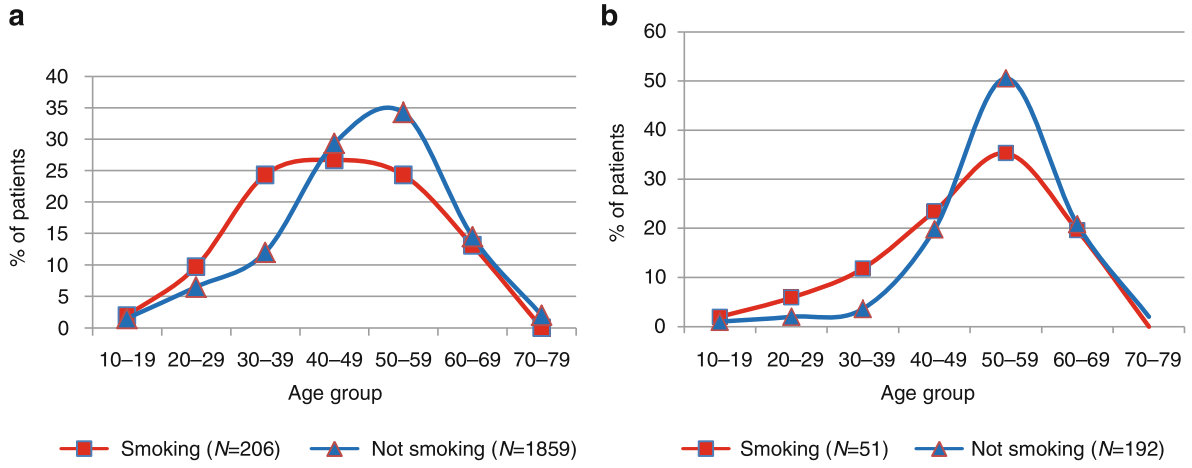

Fig. 5.4 Smoking and age of onset. (**a**) *All* patients. (**b**) Only female patients without family history

Table 5.4 Average age of onset of Dupuytren Disease with and without various comorbidities

Disease	KP	No KP	LD	No LD	LD + KP	No LD/KP	FS	No FS	IPP [a]	No IPP [a]
Average age of onset	40.8	49.1	43.9	49.2	38.8	50.0	47.8	47.6	46.5	45.9
CI (+/–)	1.25	0.55	0.9	0.6	1.65	0.6	1.1	0.6	2.1	0.75
Median	42	50	45	50	40	51	50	49	47	46
P-value	<0.001		<0.001				0.04		n.s.	
N	363	1707	609	1461	193	1291	415	1655	118	1107

KP knuckle pads, *LD* Ledderhose Disease, *FS* Frozen Shoulder, *IPP* Peyronie disease, *n.s.* not significant
[a]Male patients only; confidence interval, 0.95

5.3.4 Related Diseases

93 % of *all* respondents had Dupuytren Disease and 35 % had Ledderhose Disease. Of the patients with Dupuytren Disease, 30 % had Ledderhose Disease, 20 % Frozen Shoulder at least once (Germany alone, 8 %), 17 % knuckle pads, 12 % thyroid problems, and 5 % diabetes. 9.5 % of the male respondents had Peyronie disease. For the 4 most frequent comorbidities, knuckle pads seem to be related to an onset even earlier than Ledderhose Disease, while we find no effect of frozen shoulder or Peyronie disease on the age of onset of DD (Table 5.4). P-values were calculated by linear regression analysis using SPSS.

5.3.5 Patients' Rating of Medical Counseling

Patients were asked "Given your experience to date, how would you rank the medical community's knowledge and experience with Dupuytren Disease?" on a range of 1–10 with 1 = no knowledge, 10 = knew everything. Figure 5.5 shows results by country. For better overview the ratings 1–3 (= bad; red), 4–7 (= medium; yellow), and 8–10 (= good; green) are combined.

Table 5.5 is an attempt to analyze cultural differences, specifically whether English-speaking patients would be more reluctant to express criticism than German ones. Obviously this is not the case (see also Fig. 5.5). The differences might indicate actual difference of knowledge in the medical community. Of course, ratings of countries with very few participants, like Ireland ($N = 21$), may be more skewed by individual experiences.

5.3.6 Patients' Rating of Treatments for Dupuytren Disease

Patients were asked to rate the outcome of treatment(s) of Dupuytren Disease that they had had themselves. Treatments included in the survey were those which we had seen mentioned most in forums. If a treatment received was not listed, patients could select "Other." Each patient could rate more than 1 treatment. The scale was from 1 = made it worse to 10 = very successful (Fig. 5.6).

Verapamil is a topical crème to reduce/break down scarring. It is obviously not a very frequent treatment but was included in the survey because we knew from forums that it was not very successful and we wanted to check whether this is reflecting in this survey. "Other treatments" get a surprisingly good rating but are in detail covering a wide range of treatments (patients could explain those in the comments). Massaging was the most mentioned successful treatment in the "Other" category.

5.3.7 Comments and Suggestions from Patients

The open questions brought an overwhelming response, close to 1,900 suggestions and more than 800 additional comments. The responses often included the patient's personal experience and disease history and quite a few answers covered ¼–½ pages. *All* responses were judged valuable.

Two wishes appeared most frequently: *more research* for finding a cure, finding new treatments, and better understanding and optimizing available treatments (including success chances, hand ther-

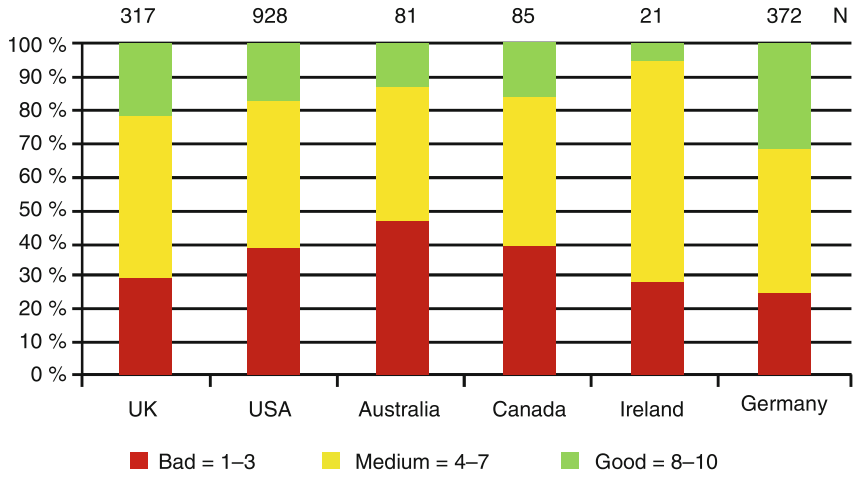

Fig. 5.5 Patients' rating of the medical community's knowledge of Dupuytren Disease by country

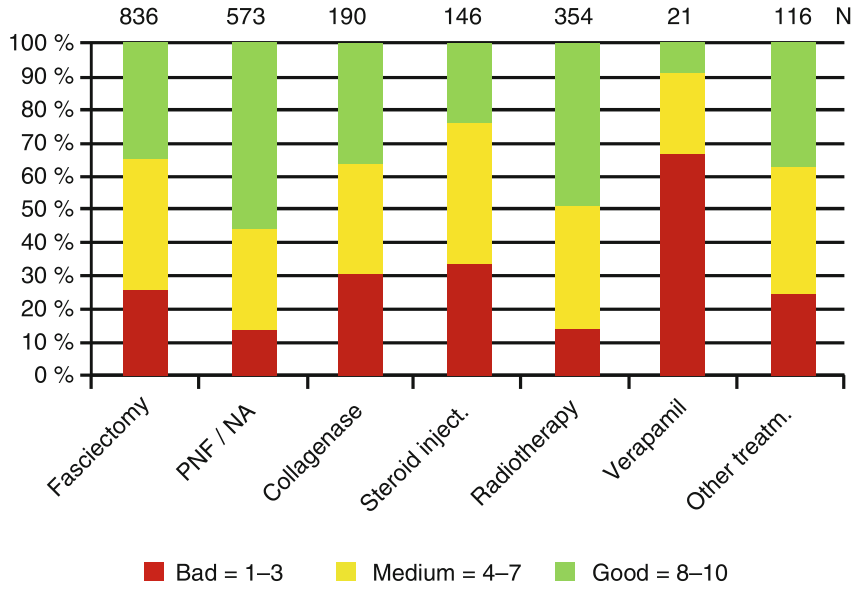

Fig. 5.6 Patients' ratings of treatments of Dupuytren Disease

Table 5.5 Rating of physicians' DD knowledge by German- and English-speaking participants (% patients)

1	2	3	4	5	6	7	8	9	10	Rating
3.8	7.5	13.4	12.1	13.4	6.7	11.6	13.4	7.5	10.5	German ($N=372$)
7.3	13	16.4	10.3	16.9	9.1	9.4	8.1	3.4	6.2	English ($N=1636$)

apy, and reducing side effects). Some comments suggested including research on Peyronie disease, one referring a specific paper (Valente et al. 2003) because the medication (arginine) had very positively affected his Dupuytren Disease.

The other frequent topic was *better education of physicians* to understand *all* treatment options and provide better counseling. Many patients were dissatisfied with the quality of information they had received, also reflecting in the ratings (Fig. 5.5).

Occasionally patients complain that GPs may recognize Dupuytren Disease but are not aware of possibly related diseases like Ledderhose, Peyronie, or Frozen Shoulder.

Quite a few patients had familiarized themselves through the Internet about treatment options but had difficulties finding a medical provider. While surgery seemed to be generally available and surgeons have successfully been made aware of collagenase, a frequent request is making PNF and radiotherapy more available.

Comments from Patients

Quality of counseling: "The information on treatment options needs to be shared more, i.e. get it into orthopedic training"; "I believe that hand surgeons or diagnosticians should be held accountable if they do not advise patients about *all* the available treatments"; "I had a ray amputation on my little finger which could have been prevented if I had been referred earlier. I took advice from my GP and feel badly let down"; "Misdiagnosis: 'We won't know what it is unless we cut it open and remove it'. And that operation caused a flare up of nodules"; "The hand surgeon said later that he didn't recognize it as Dupuytrens. Cutting into the bump with the idea of removing it started the disease to advance quickly".

Documentation: "I believe that follow-up data needs to be collated and analysed for presentation to District Health Boards, insurers and other funding organisations to enable fact-based decision making in the context of DD, the lifetime cost of treatment and the quest for the most positive health outcomes."

Massaging as treatment: "I had started forming a habit of massaging it daily. I still massage it every day and it has basically not returned"; "I started applying frequent friction to my Dupuytren's hands by rubbing my thumb back and forth over it and after about a month it started to reduce in size. I have noticed about an 80 % improvement doing this."

Pathogenesis: "Over the past few years I have started to get the feeling that DD/LD have a genetic and an environmental trigger. The genetic seems to occur younger and is more aggressive, while the environmental trigger seems to be more local and less aggressive. Environment triggers could be alcohol, diabetes, hand injury or maybe just old age. Could this be so and if it is, should the treatment options be different?"

Improvement of this survey: "more options for fill in responses, more guidance for questions that have a 1–10 rating scale, or better yet replacing a single question scale by a collection of sub-questions that would lead you to better overall data and understanding. I do not think that anyone taking this survey would be put off at *all* by having to answering a much longer and more detailed questionnaire"; "given the length of presence of the disease, i do not think the questions adequately gave a true picture … the complications of tendon issues, nerve damage, arthritis in the progression of the disease were not addressed"; "I do think your survey could have been better served with a question rating the affliction's impact on quality of life"; "I think that *all* the information about this disease should be gathered in one big database".

Patients emphasize that DD can be quite painful. Improved listening skills of the physicians were requested several times. Regular and frequent massaging seems to be beneficial for some patients.

5.4 Discussion

This survey was conducted to assess the quality of counseling and treatment as perceived by patients with Dupuytren Disease and to better

understand what patients need and are missing. Additionally, the effect of drinking, smoking, and family history, as well as comorbidities, should be evaluated. To our knowledge this survey is one of the largest surveys of DD patients that has been conducted so far, and it is the first survey with patients rating therapies.

5.4.1 Ratings of Counseling and Therapies

Ratings of consultation and of treatments inquired through an anonymous questionnaire are likely more honest than if patients are interviewed by their treating doctor. We consider these ratings as a key element of our survey.

The ratings of the knowledge of the medical community are generally disappointing (Fig. 5.5). One would hope and thrive for >50 % good ratings but no country is achieving this (potential biases see Sect. 5.4.3). The UK and Germany are doing relatively well but *all* countries exhibit room for improvement. The specifically bad rating for Ireland is statistically not very relevant. The knowledge of therapies and their side effects might be an area that – in part yet to be established – Dupuytren Societies could gradually improve.

The ratings of therapies (Fig. 5.6) show about equal ratings for fasciectomy, PNF, and collagenase injection. PNF is leading but might be influenced by the possibly positive US bias as discussed below in paragraph 5.4.3. Collagenase and fasciectomy are very similar. Obviously *all* three treatments have their place and have – in the patients' view – good as well as not so good outcomes. There is still room for improvement for *all* therapies according to patients' comments. Bad experience with surgery included pain, slow recovery combined with long hand therapy, disease extension, and damage to the hand. PNF seems to be well tolerated; dissatisfaction focused mainly on quick recurrence (several patients mention that they ended up having surgery). Collagenase injection was criticized for swelling and pain, recurrence, and price. Further surveys investigating into details of negative and positive ratings might help finding improvements for each treatment.

Ratings from patients may differ from ratings from surgeons. Dias et al. (2013) found for Europe "overall, 97 % of the procedures were rated by the surgeon as having a positive outcome" while about 25 % of the patients of our survey are rating the results of fasciectomy as bad. Obviously criteria are different, emphasizing the importance of understanding expectations and needs of patients prior to treatment (Carboni et al. 2015). Our results are matching better with those of Dias and Braybrooke (2006), who interviewed 1,177 British patients after surgery and report that 10 % had no improvement and another 9 % considered their deformity worse after surgery.

By far the best rating is for radiotherapy, confirming its role as treatment for the early stage of Dupuytren Disease, prior to contracture. Negative comments referred mainly to inefficiency in stopping the disease and in some cases to burning sensation and inflammation.

5.4.2 Comparison with Other Surveys

So far only few studies surveyed more than 1,000 DD patients (Dias and Braybrooke 2006 ($N=1{,}177$), Loos et al. 2007 ($N=2{,}919$), Anthony et al. 2008 ($N=1{,}815$), Dahlin et al. 2013 ($N=3{,}357$) together with Dias et al. 2013 ($N=3{,}357$), Eaton 2016a ($N=3{,}120$)). Most of them analyzed patient charts retrospectively; only Dias and Braybrooke surveyed DD patients directly (after they had surgery).

In our survey we have a male/female ratio of 1.4, which coincides with results of Lanting et al. (2013), who did a systematic epidemiology of the Dutch population. This is far less than the ratio of 3.4 observed by Mikkelsen (1972) in Norway. Anthony et al. (2008) find in Boston, USA, in hospitals a gender ratio of 1.7. Other hospital-based ratios are in part much higher, up to 10 (Mikkelsen 1972; Loos et al. 2007). Our average age of 59 is lower than the 62 of Lanting et al. but our data set includes young patients, while Lanting et al. researched only patients of 50 years or older.

Dolmans and Hennies (2012) reported the age of onset in 1,000 Dutch Dupuytren patients

undergoing surgery. While their results qualitatively agree with ours, they are seeing more patients with a later onset. They find that the onset for female patients is peaking in the age group 50–59 (D&H: 34 %; this survey 42 %) but they find still high percentages in the 60–69 age group (D&H: 26 %; this survey 16 %). This sharper drop-off of our data confirms that our survey covered a younger population. While we find an average age of onset of 46/50.1 (m/f), Dolmans and Hennies report an average age of first surgery of 58/61 (m/f), interestingly about the same time difference.

Becker et al. (2014) interviewed patients undergoing fasciectomy or PNF at several German and Swiss hospitals and clinics. They found that positive family history correlates with disease in both hands, recurrence, knuckle pads, and Ledderhose Disease. They do not report a strong effect of alcohol or smoking, in agreement with Loos et al. (2007). While only 5 % of our patients report having diabetes, Becker at al. are finding 14.5 %, Dahlin et al. (2013) in Europe an average of 28 %, and Descatha et al. (2014) 16.7 % in the French GAZEL study (999 patients; average age 68 for men, 65 for women). In a more detailed analysis, Lanting et al. (2013) report diabetes in Dutch Dupuytren patients in the age group 50–55 at 3.7 % and in the age group 56–65 at 11.6 %, demonstrating strong age dependence. The 5 % diabetes that we find at an average age of 59 is approximately matching with the data of Lanting et al. and the slightly older patients set (average age 61.6, 7 % diabetes) of Seegenschmiedt et al. (2012).

Originally the authors had planned comparing percentages of comorbidities with the normal population, but the span of reported "normal" percentages, as discussed above for diabetes, the country dependence, and gender and age dependence are aggravating comparison. For Peyronie disease a prevalence of 0.5–13 % has been reported for the male US population, depending on definition (DiBenedetti et al. 2011), making it difficult to decide whether the 9.5 % found in this survey are just normal. Our observation that having knuckle pads is related to an earlier onset of DD, Ledderhose Disease somewhat less but still measurable, and Peyronie disease having very little or no effect are in agreement with genetic research on diathesis (Dolmans et al. 2012).

Descatha et al. (2014) found a dose relationship of drinking with Dupuytren Disease (affecting prevalence). One reason why we don't observe any effect on the age of onset may be the differently scaled question: Descatha et al. asked for <3 glasses/day, 3–4 glasses/day, and ≥ 5 glasses of wine/beer or ≥ 3 glasses of spirits per day. In the Descatha (GAZEL) study, only 20.8 % are in the lowest category (<3 glasses), while at least 70 % our patients would fall into that category (Table 5.1), which might indicate more heavy drinkers in the GAZEL sample but also problems in self-reporting of drinking habits. Lanting et al. (2013) find a clear effect of alcohol consumption on the prevalence already at about 2 glasses/day.

Eaton (2016a) finds that the percentage of Dupuytren patients also suffering from Ledderhose is clearly related to the age of onset of Dupuytren Disease. This is in remarkable agreement with our data (Fig. 5.7a).

To test whether our data are influenced by an overlap with data from Eaton, a subset of our data (German and British patients only = D + UK in Fig. 5.7a) is also shown, confirming this trend. A possible explanation would be that the age distribution of LD falls off more sharply than for DD but this does not seem to be the case (Fig. 5.8).

Another explanation could be that having both, Dupuytren and Ledderhose Disease, indicates stronger diathesis, while developing Dupuytren Disease late is indication of weak diathesis. Yet this would apply for both, Fig. 5.7a, b and cannot explain the difference. Dolmans et al. (2012) found only a weak link between genetic risk for Dupuytren Disease and Ledderhose Disease. The relation between both diseases deserves further investigation.

5.4.3 Potential Bias and Errors

Participants have not been randomly included in the survey but were invited through mailing lists, websites, and forums. For example, the mailing list of the Dupuytren Foundation might include a relatively high percentage of PNF-treated patients because it includes many former US

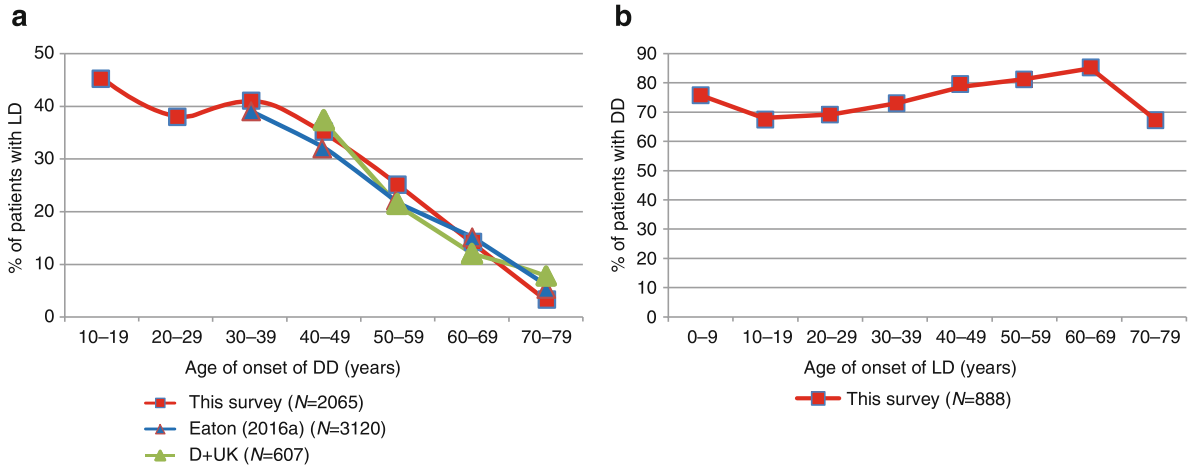

Fig. 5.7 Percentages of patients suffering from DD and LD. (**a**) Percentage suffering from Ledderhose Disease vs. age of onset of Dupuytren Disease. (**b**) Percentage suffering from Dupuytren Disease vs. age of onset of Ledderhose Disease

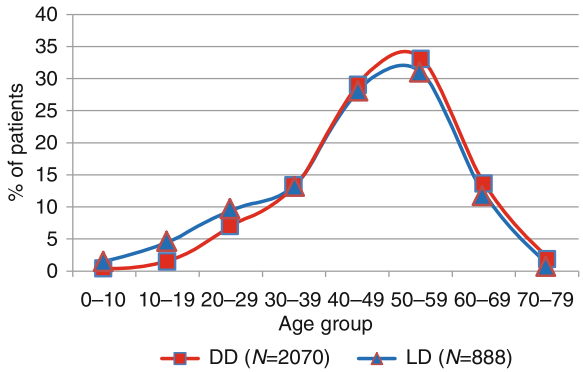

Fig. 5.8 Age of onset of DD and LD

Table 5.6 Average patient ratings of PNF, surgery, and radiotherapy in three countries

Country	USA	UK	Germany
PNF	7.6	5.9	6.4
Surgery	5.9	5.3	5.4
Radiotherapy	7.3	6.8	6.1

patients of Dr. Charles Eaton and those might be more satisfied with PNF than patients from elsewhere, indicated by comments like "I give *ALL* 10 stars to Dr. Charles Eaton who did an amazing NA on my very warped hands" or "… he was god sent."

To check this, we compared ratings of PNF, surgery, and radiotherapy by country (Table 5.6).

Obviously patients from the USA were generally giving better ratings, maybe indicating a cultural difference. This effect is specifically pronounced for PNF, supporting the suspicion of a slight and positive bias of our data regarding PNF in the USA. Of course, the different ratings might also in part reflect different qualities of treatment in those countries.

Bias might also be created in the data because patients visiting forums might be doing this because they had been dissatisfied with their previous treatment. Satisfied patients are more likely to not do anything. So we might have a general bias toward worse ratings. That also applies to ratings of the medical community. Specifically patients dissatisfied with the consultation received may have started educating themselves on the Internet and by doing so ended up on our websites.

Another bias might be induced by using the Internet for this survey, for invitations as well as filling it out. We are more likely covering the younger part of the Dupuytren patients. The average age of our participants is 59. Yet the average onset of the disease is 48 meaning that on an average, our participants have had about 10 years of experience with Dupuytren Disease. We do not expect that a slightly lower age of the participants has affected ratings.

Although we had no complaints about the questionnaire being too complicated, using an online, not assisted, self-reporting instead of medical records may be subject to misunderstandings, entry errors, and recall errors.

Conclusions

- For patients it is important to find a doctor who is able to inform them about *all* treatment options and to provide good counseling which treatment is optimal for the patient's specific situation; for doctors it is important to understand the patient's personal preferences.
- None of the established treatments of Dupuytren Disease receives overall good ratings from patients. Further research is required comparing treatments and to understand and improve specific shortcomings. Additionally, PNF and radiotherapy are lacking availability in some countries.
- Smoking and family history cause earlier onset of Dupuytren Disease. We don't see an effect of moderate drinking on the age of onset (heavy drinking and prevalence were not analyzed).
- Online surveys offer an easy and versatile means for evaluating patients' perceptions. The disadvantage of online surveys is that there is no control of the quality of input and no possibility to contact the patient in case of further questions. Building a Dupuytren database including patient contact data would help (Eaton 2016b).

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