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Conaghan, PG, Porcheret, M, Kingsbury, SR et al. (11 more authors) (2014) Impact and therapy of osteoarthritis: the Arthritis Care OA Nation 2012 survey. Clinical Rheumatology. ISSN 0770-3198

https://doi.org/10.1007/s10067-014-2692-1

Title: Impact and therapy of osteoarthritis: the Arthritis Care OA Nation 2012 survey

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Running title: Impact of OA and its therapy

Abstract

Osteoarthritis (OA) is the fastest growing cause of disability worldwide. The aim of this study was to understand the impact of OA on individuals and to explore current treatment strategies. An online UK-wide survey of people with self-reported OA was conducted composed of 52 questions exploring the impact of OA, diagnosis and treatment, the role of health professionals and self-management. 4,043 people were invited with 2,001 respondents (49% response, 56% women, mean age 65 years). 52% reported that OA had a large impact on their lives. 15% of respondents had taken early retirement, on average 7.8 years earlier than planned. In consultations with general practitioners, only half reported a discussion on pain; fewer reported discussing their fears (21%) or management goals (15%). Nearly half (48%) reported not seeking medical help until pain was frequently unbearable. Oral analgesics (62%), topical therapies (47%), physiotherapy (38%) and steroid injections (28%) were commonly used. The majority (71%) reported varying degrees of persistent pain despite taking all prescribed medication. Although 64% knew that increasing exercise was important, only 36% acted on this knowledge; 87% who increased exercise found it beneficial. Over half had future concerns related to mobility (60%), maintaining independence (52%) and coping with everyday activities (51%). OA had significant individual economic impact especially on employment. Current treatment strategies still leave most people in pain with significant fears for the future. There is considerable opportunity to improve the holistic nature of OA consultations especially in provision of information and promotion of self-management strategies.

Key words: Osteoarthritis, primary health care, employment, therapy

Introduction

Osteoarthritis (OA) is the most common form of arthritis and the fastest growing cause of disability worldwide, largely due to rapidly ageing and increasingly obese populations [1]. Each year 8.75 million people in the UK seek treatment for OA [2, 3]. Within the next 20 years, 25% of the UK population will be over the age of 65, 50% will be clinically obese and the number of people with OA is predicted to almost double [4].

OA confers an enormous burden on individuals and their families. Quality-of-life studies suggest the impact of OA to be comparable to that of cardiac, neurological, and pulmonary diseases.[5-7] OA is also the leading cause of absence from work, costing the UK economy upwards of £18 billion annually and together with other musculoskeletal diseases accounts for almost one-tenth of the total annual NHS budget (£10 billion annually) and 12% of primary-care consultations [4, 8]. Improving health-related quality-of-life for people with long-term conditions such as OA is a current NHS priority [9].

Current guidelines for the management of OA recommend pharmacological and non-pharmacological therapies. However, these therapies may only be mildly effective and pharmacological treatments are substantially limited in clinical application by side-effects, particularly in the elderly [10, 11].

The impact of OA on individuals and how therapies are used is still relatively under-studied and offers opportunities to improve current therapeutic strategies. The aim of this study was to understand the impact of OA on important activities such as employment and to explore how individuals are treated and how they use their therapies.

Methods

Survey design and conduct

An online survey was designed in conjunction with an advisory board group comprised of three rheumatologists together with a general practitioner (GP), physiotherapist, pharmacist, nutritionist, psychologist and representatives from a patient charity (Arthritis Care). An online format was chosen since studies suggest that participants are more likely to respond to questions about sensitive subjects, such as health and ability to live everyday life with a potentially debilitating illness, when questions are asked in an on-line format [12]. The survey was composed of 52 questions exploring the impact of OA, diagnosis and treatment, the role of health professionals and self-management, including the role of activity and sport. Each question had a series of set answers, designed by the advisory board, with the option to provide additional information where applicable (see Supplementary Material).

The survey was completed online between November and December 2011. The survey population were people with self-reported OA who were randomly selected from a large UK research panel of 390,000 adults who have registered an interest in survey participation. The research panel were sent a pre-screening survey asking whether they suffered from a range of illnesses, including OA. A sample was randomly selected by computer from respondents who self-reported OA, with approximate quotas for age and gender to ensure a representative sample. Invitations to complete the full survey were emailed to 4,043 members of the research panel. The study was conducted in line with the Market Research Society's code of conduct. All survey responses were fully anonymised.

Data analysis

To standardise the study population to a UK OA population, data were weighted back to the national prevalence of OA according to age and gender, using data from the RCGP Birmingham database [13]. Descriptive statistics were used to present data according to the questionnaire categories. In some categories, respondents were able to include more than one response; therefore data could exceed 100%.

Results

Population characteristics

Responses were obtained from 2,001 of the 4,043 people invited to participate in the survey (overall response rate of 49%). Of the respondents, 56% were women, the mean age was 65 years (range 19-91 years), and the mean number of joints affected by OA was four. Knees were ~~,~~ the most commonly affected joint~~knees~~ (66%;n=1323/2001), followed by hands/fingers (54%;1087/2001), ~~and~~ hips (43%;864/2001), lower back (37%;747/2001), neck (35%;701/2001), shoulders (29%;572/2001), feet/toes (27%;534/2001) and ankles 19%;373/2001). The mean age of diagnosis was 55 years, with respondents reporting an average of 2.8 years between symptom onset and diagnosis of OA. Painful joints was the most common initial symptom (88%;n=1757/2001), followed by stiffness (53%;n=1060/2001) and swollen joints (38%;n=768/2001). Both men and women believed genetic factors as the most likely cause of their OA (Table 1). Women were more likely to consider being overweight as a cause, while men were more likely to attribute their OA to sport, sports-injury or work.

The impact of OA on individuals

More than half of respondents (52%;n=1038/2001) reported that OA had a large impact on their life; 79% (n=1585/2001) had given up or reduced an activity due to OA, including stopping/reducing exercise or stopping/reducing walking. Significant difficulty was reported with daily activities (Table 2). Respondents also reported a large impact on their social lives and emotional well-being.

Early retirement as result of OA was reported by 15% (n=296/2001) of respondents, by an average of 7.8 years. Of those aged under 65 (n=287), more than one quarter (28%;n=79/287) had given up work and a further 15% (n=43/287) had changed their type of work or reduced their hours. OA was also reported to have affected the lives of partners, with 5% (n=15/287) stating their partners had either stopped working or reduced their hours to care for them.

In addition to loss of earnings, OA was reported to have led to increased personal costs for 64% of respondents (n=1283/2001), including extra heating (28%;n=579/2001), travel (26%;n=523/2001) and parking (16%;n=314/2001) for healthcare services, treatment and prescription costs (18%;n=366/2001), and adjustments to the home (15%;n=304/2001), totalling an average of £480 per person annually. The large majority received no state benefits (72%;n=1441/2001); 30% (n=600/2001) had a disability parking blue badge and 18% (n=366/2001) claimed disability living allowance.

Treatment of OA

The majority of people (90%;n=1807/2001) reported that they had visited their GP at least once, whilst 56% had seen a hospital specialist and 46% a physiotherapist about their condition (Table 3). After diagnosis, 40% (n=719/1754) continued to visit their GP regularly. Men were more likely to consult their GP compared to women (61%;n=447/735 vs 48%;n=612/1266). Women more frequently used written material, including magazine articles (35%;n=437/1266) or leaflets (25%;n=311/1266), or consulted friends and family (21%;272/1266). Nearly half of all respondents (48%;n=961/2001) would not seek medical help until their pain was frequently unbearable; women (53%; n=669/1266) were more likely to wait until the pain was unbearable than men (40%; n=292/735).

Overall, the majority reported that appointments with their GP (70%;n=1231/1754) or hospital specialist (63%;n=927/1466) were very/quite valuable; however 20% (n=293/1466) reported that visits to a hospital specialist were not at all valuable, compared to 7% (n=120/1754) for GP visits. Two-thirds of respondents believed their GPs gave them the time they needed (67%;n=1176/1754), whilst about half felt they were given the treatment they needed (49%;n=863/1754). This reduced to 42% (n=618/1466) and 42% (n=613/1466) respectively for hospital specialists. In consultations with either the GP or hospital specialist, pain management was the most common topic discussed (Table 4), followed by impact of OA on daily life and the importance of diet and exercise. Fears and goals of management were seldom discussed, and only 15% had been directed to further sources of information and support. Over half of respondents (59%;n=1119/1887) felt they had not agreed a care-plan with their GP or hospital specialist, 49% (n=933/1887) would have liked to have been given further information about other areas that could affect their OA, including diet and exercise.

The majority (95%;n=1887/2001) had used some form of pharmacological or non-pharmacological treatment for their OA, with 13% (n=248/1887) reporting treatment to be very effective and 48% (n=902/1887) reporting treatment to be fairly effective. Respondents had tried an average of three treatments; most commonly prescription oral analgesics, topical therapies, physiotherapy, steroid injections and over-the-counter (OTC) medications (Table 5). A quarter had had a joint replacement for their OA. Half (50%;n=620/1237) used their prescribed medications every day. One-third took their medication irregularly (n=395/635), following advice from their doctor, whilst a further 14% (n=156/635) reported irregular use of painkillers without advice to do so. OTC medication was mainly used due to the GP not prescribing any medication (26%;n=132/515), prescription medication not relieving pain (20%;n=103/509) or as a way of reducing the medication costs (16%;n=81/509). Most reported that their GPs were aware of their use of OTC medications (69%;n=347/509), with 44% (n=222/509) being advised by their GPs to use OTC medication. A large majority (71%;n=1420/2001) reported varying degrees of persistent pain despite taking all prescribed medication; 12% (n=250/2001) described the pain as often unbearable.

Awareness of self-management was generally much higher than take-up (Table 6). For example, whilst 75% of people were aware that they needed to lose weight, only 42% were actively trying to lose weight. Almost half did no exercise (defined as any activity specifically designed for the purpose of health or recreation which has the effect of raising the heartbeat) (44%;n=873/2001). Of those that had used self-management strategies, most reported that they had helped to some extent (Table 6).

Future concerns

Almost half of respondents (46%;n=922/2001) believed that OA was not a priority to the NHS, only 14% felt that OA was given the attention it deserved and 15% that OA was becoming more of a priority for the NHS. Over half of respondents were very, or fairly, concerned about their mobility in the future (60%;n=1201/2001), whilst concerns about maintaining independence (52%;n=1049/2001), coping with everyday practical activities (51%;n=1016/2001) and becoming isolated (45%;n=892/2001) were also commonly reported.

Discussion

This study demonstrates that OA has a significant physical, emotional and financial impact on individuals: restricting participation and performance of routine daily activities, limiting earning potential while causing increased expenditure. Many people report waiting until symptoms are unbearable before seeking help. Most people in this study population had tried multiple treatments for OA. Two-thirds reported their medications to be at least partly effective, however a similar proportion reported to be in persistent pain or to have functional restrictions despite use of medications. Provision of information on the NICE core recommended treatments for OA (exercise and weight-loss) [10] was low, and although respondents demonstrated good awareness of their benefits, uptake of these self-management strategies was poor. Overall, people with OA had considerable concerns about the future, particularly about restricted mobility and loss of independence.

The results of this study support previous literature demonstrating the broader impact of OA on individual's lives [14-16]. Notably, our study highlights that the impact of OA is not limited to the individual but also stretches to their family/carers. Literature examining the impact of OA on work participation remains conflicting, in part due to variations in study design and cohorts examined. Four studies have reported OA to be independently related to occupational limitations, reduced job effectiveness, being out of work and sick leave, with 75% of workers with OA in one study reporting the need for some kind of work adaption due to their OA [17-19]. However, in two further studies equivalent work participation rates were observed in OA and healthy populations.[20-22] The literature is also conflicting regarding forced early retirement due to OA, with a recent meta-analysis failing to find a significant relationship [19]. Together these studies suggest that OA may cause reduced productivity in a substantial proportion of workers with OA, with sick leave and early retirement limited to a smaller proportion of the OA population. Improved support to individuals, in terms of occupational and ergonomic interventions, is particularly pertinent now increasing numbers of people are working to an older age.

The direct and indirect costs of OA in Europe have been estimated at 0.5% of gross national product.[23-27] However there are no published studies that address direct or indirect costs of OA in the UK. This study suggests a significant proportion of people with OA are faced with increased living expenses as a result of their condition, whilst at the same time often having reduced earning potential. Notably, only a minority reported receiving state benefits.

An estimated 21% of the adult population consult their GP with a musculoskeletal problem over the course of a year, mainly due to OA [8, 28]. In this study, one in five reported to never returning to their GP about their condition after the first visit and a large proportion would not consult until pain was unbearable, reflecting a recent meta-analysis which reported that patients often wait to visit their GP until symptoms reach a critical point [29]. These findings re-emphasise previous reports of the perception that ‘nothing can be done’ and that OA pain is seen as part of aging [30]. There is a perceived pessimism amongst people with OA about the availability, effectiveness and risk attached to treatments [29, 31-

34]. As highlighted by previous studies, consultations with healthcare providers are reported to focus mainly on pain control, with little discussion on the impact and fears of the individual and long-term management plans. Previous reports have suggested frustration in individuals at the lack of understanding amongst healthcare professionals of the impact of OA [33]. reflecting the findings of this study where only a minority discussed OA impact with their doctor. Whilst further information and support is available to people with OA, this study suggests that healthcare professionals frequently do not highlight these to patients.

Most respondents had tried, or were using, some form of medication for OA, with 61% reporting treatment to be fairly or very effective. Notably, a similar proportion reported being in constant pain despite medication, suggesting a perception that treatment will only partially relieve symptoms [30]. Prescribed medications were used by two thirds of respondents and use of OTC medications was in line with previous studies, with GPs generally aware of this use [35, 36]. Irregular use of medication was common, and in line with previous reports, highlighting the previously reported perception that individuals are concerned about developing tolerance to medications and only using medication when really needed.[33] Non-pharmacological therapies were less widely used. Recommendation of weight loss and exercise was low, suggesting a focus on pharmacotherapies [37]. These findings are generally in line with other studies suggesting that pharmacological therapies are used more frequently in this population [35, 36]. Previous studies have indicated that advice on weight loss is given to less than half of obese adults with arthritis [37, 38]. Together with previous studies, the results of this study suggest that there is still a considerable gap between evidence-based and reported practice.

The study does have some limitations. Due to use of an online survey, there may have been some bias in the population who responded to the survey. However, the characteristics of the study population, including median number of painful joints and age of diagnosis, align with previous population data, supporting the generalizability of our survey data [39, 40]. The retrospective nature of the survey may have introduced recall bias. Although the option of recording additional answers not covered by the set text was offered for most questions in the survey, the set answers offered may have influenced responses and thus survey results.

In summary, this study demonstrates that osteoarthritis has significant impact on individuals with considerable pain, reduced daily activities, reduced ability to work and increased costs. Many people do not seek help until symptoms are severe and current treatment strategies still leave most people in pain with significant fears for the future. Self-management strategies were reported to be effective when employed; however despite good awareness of self-management amongst respondents they were considerably under-utilised, suggesting that current support for self-management may require optimisation. Self-management for long term conditions is a current priority of the NHS, and a core component of guidelines for the treatment of OA [41, 42]. Further work to support implementation of self-management by people with OA is an important direction for clinical practice and future research.

Ethical Approval: The study was conducted in line with the Market Research Society's code of conduct. REC review was not required as participants were self-reporting and not identified through the NHS. ~~.~~

Funding: PGC and SRK are funded in part by Arthritis Research UK and the NIHR Leeds Musculoskeletal Biomedical Research Unit.

Disclosures: NONE.

Acknowledgements

The following companies have provided a sponsorship grant towards this independent programme to support OA Nation 2012: AstraZeneca, Napp Pharmaceuticals Limited, Pfizer Limited and Sanofi. These companies have also provided limited support and advice to

Arthritis Care in relation to the collation of data for the project. However, editorial control of materials and decisions regarding OA Nation 2012 remain with Arthritis Care.

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Tables

Table 1: Factors believed to have caused the development of OA

Cause of osteoarthritis	Total n (%) n=2001	Males n (%) n=735	Females n (%) n=1266
Genetics / inherited from previous generations	792 (39.6)	216 (29.4)	576 (45.5)
Doing a lot of sport / activities	350 (17.5)	216 (29.4)	134 (10.6)
A sports injury	275 (13.7)	171 (23.3)	104 (8.2)
The type of work that you do	372 (18.6)	160 (21.8)	212 (16.8)
A work injury	169 (8.5)	88 (12.0)	81 (6.4)
A non-work injury (e.g. motor accident)	260 (13.0)	77 (10.5)	182 (14.4)
A hobby	162 (8.1)	46 (6.3)	116 (9.2)
Being overweight	425 (21.2)	136 (18.5)	289 (22.8)
Other activity	215 (10.7)	58 (7.9)	157 (12.4)
Don’t know	285 (14.2)	93 (12.7)	191 (15.1)

Table 2: Activities that are affected by OA

Impact on daily activities **n (%)** **n=2001**		**Impact on social activity and emotional health** **n (%)** **n=2001**	
Struggle with any activity	1696 (84.8)	Any impact on life	1585 (79.2)
Going up and down stairs	1273 (63.6)	Walking	1049 (52.4)
Gardening	1143 (57.1)	Exercise	995 (49.7)
Getting out of a chair	965 (48.2)	Emotional health	720 (36.0)
Getting around	918 (46.0)	Travelling / holidays	378 (18.9)
Carrying out daily tasks	816 (40.8)	Crafts and hobbies	365 (18.2)
Going to the shops	672 (33.6)	Work	340 (17.0)
Getting out of bed	620 (31.0)	Socialising	232 (12.0)
Getting dressed	584 (29.2)	Intimacy	182 (9.1)
Making meals	366 (18.3)	Meeting with friends	101 (5.1)
Working	347 (17.3)	Using technology	33 (1.7)
Looking after children / grandchildren	297 (14.8)	Other	239 (12.0)
No impact on daily activities	305 (15.2)	No impact on social activities	416 (20.8)

Table 3: Healthcare professionals or support services seen about OA

Healthcare professional	Have ever used for OA n (%) n=2001	Would like to have access to for OA n (%) n=2001
GP	1807 (90.3)	41 (2.1)
Pharmacist	170 (8.5)	32 (1.6)
A practice nurse	324 (16.2)	78 (3.9)
A hospital specialist	1128 (56.4)	198 (9.9)
A pain specialist	288 (14.4)	373 (18.6)
A physiotherapist	916 (45.8)	192 (9.6
A nutritionist	87 (4.4)	134(6.7)
Social services	119 (6.0)	54 (2.7)
A charity or support group	36 (1.8)	86 (4.3
A close friend / family member	810 (40.5)	21(1.1)
A complementary therapist (e.g. acupuncturist)	318 (15.9)	213 (10.6)
Other	67 (3.4)	177 (8.9)
Spoken to any healthcare professional	1942 (97.1)	-
I wouldn’t like to access anything else for my osteoarthritis	-	960 (45.0)

Table 4: Areas discussed during consultations with GPs and specialists

Area discussed	GP n (%) n=1754	Hospital specialist n (%) n=1466
Impact of osteoarthritis on everyday life	605 (34.5)	393 (26.8)
Concerns and fears around osteoarthritis	362 (20.6)	244 (16.6)
How to manage the pain of your osteoarthritis	945 (53.9)	448 (30.6)
Goals for managing osteoarthritis	262 (14.9)	213 (14.5)
Exercise and diet	503 (28.7)	246 (16.8)
Other healthcare support available	282 (16.1)	186 (12.7)
Other support for osteoarthritis (e.g. patient groups)	142 (8.1)	51 (3.5)
Other	179 (10.2)	139 (9.5)
Don’t know	401 (22.9)	573 (39.1)

Table 5: Types of therapies used to alleviate OA-related pain and other symptoms

Therapy	**n (%)** **n=2001**
Prescribed medications	1237 (61.8)
Anti-inflammatory gel	931 (46.5)
Physiotherapy	764 (38.2)
Steroid injections directly into the joint	550 (27.5)
Over-the-counter medications	509 (25.4)
Joint replacement	498 (24.9)
Transcutaneous electrical nerve stimulation (TENS)	400 (20.0)
Nutritional supplements	325 (16.2)
Acupuncture	294 (14.7)
Herbal remedies	238 (11.9)
Assistive devices: braces/support	230 (11.5)
Training on how to manage your osteoarthritis yourself	151 (7.6)
Hydrotherapy	141 (7.1)
Hot and cold therapy (thermotherapy)	121 (6.1)
Capsaicin gel	71 (3.6)
Viscosupplementation	3 (0.2)
Other	172 (8.6)
None of these	90 (4.5)

Table 6: Awareness, use, and perceived benefits of self-management activities to alleviate OA symptoms or slow OA progression

Self-management Activity	**Awareness that activity may reduce symptoms of OA n (%) n=2001**	**Activity undertaken n (%) n=2001**	**Activity perceived to be beneficial n/N (%)**
Reviewing diet	1026 (51.3)	873 (43.6)	688/873 (78.8)
Losing weight	1491 (74.5)	847 (42.3)	702/857 (81.9)
Increasing/changing exercise	922 (46.1)	716 (35.8)	621/716 (86.7)
Making adjustments at work e.g. using gadgets to make tasks easier	757 (37.8)	299 (14.9)	201/299 (67.2)
Using walking / mobility aids	994 (49.7)	720 (36.0)	-
Making adjustments in the home	995 (49.7)	543 (27.1)	501/543 (92.3)
Other	183 (9.2)	240 (12.0)	-