Impact of impaired morning function on the lives and well-being of patients with rheumatoid arthritis

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Morning joint stiffness and pain are prominent features in patients suffering from rheumatoid arthritis (RA) and contribute to impaired function. A survey was conducted across 11 European countries to assess the impact of impaired morning function on patients’ quality of life. A total of 518 rheumatologists, and 750 patients aged 18–75 years with RA for ≥ 6 months and impaired morning function at least three times a week, completed the structured questionnaires. Impaired morning function was defined as ‘stiffness and pain in the joints first thing in the morning that results in difficulty to function or perform tasks’.

The mean duration of morning stiffness and pain was 83 min according to patients, slightly longer than that estimated by rheumatologists (70 min). Impaired morning function lasting more than 30 min/day was reported by 75% of patients, with 76% of rheumatologists estimating this duration for their patients. Most respondents (82% of patients and 96% of rheumatologists) considered that impaired morning function had a significant effect on patient quality of life. Around two-thirds of patients reported changes in how they carry out usual morning activities. Patients who were unable to function normally in the morning reported feeling frustrated (58%) and angry (32%). Almost one in five patients in the survey (18%) was unable to work as a direct result of their RA. Of the 274 patients included in the survey who were in paid work, 73% reported that impaired morning function had a significant impact on their job; 40% missed time from work in the past 6 months due to impairment in morning function, resulting in a mean of 4.5 days lost from work/employed person.

In conclusion, the survey shows that impaired morning function has a considerable impact on the lives and well-being of patients with RA.
professional identification, patient associations, existing panels of the general public, and newspaper advertisements. Patients aged 18–75 years were included in the survey if they had RA diagnosed at least 6 months previously. As the survey was designed to assess the impact and not the incidence of impaired morning function, only patients with such symptoms on at least 3 days/week were included. Impaired morning function was defined as ‘stiffness and pain in the joints (particularly the hands) first thing in the morning that causes reduced strength, grip and mobility and results in difficulty to function or perform tasks’. Quotas for recruitment were used with the aim of including approximately 70% females, with 25–30% of respondents in each of the age ranges 18–45, 46–55, and 56–65 years, and 10–25% aged 65–75 years.

Rheumatologists recruited to the survey were existing participants in online physician panels. Rheumatologists were included if they spent at least 20% of their time in direct patient care, were currently treating patients for RA, and seeing patients who they considered experienced impaired morning function. Rheumatologists completed the questionnaire online.

**Results**

**Qualitative findings**

Five in-depth interviews and one focus group were conducted in Sweden and the UK, respectively, to help to identify relevant issues. This phase of the research revealed that patients with RA describe their symptoms in a variety of ways, with ‘pain’ and ‘stiffness’ the terms most commonly used. On waking up, patients described feeling stiff, tired, locked, aching, and painful: ‘Can hardly move at all’; ‘In the morning I feel dreadful’. Although a minority of patients interviewed got up straight away, there was generally a period of adjustment in bed: ‘I recover in bed until the worst is over’.

Patients described the period of leaving bed as hard to get up, begin to move around, wobbly, unstable, unsteady, hobble around. They described starting the day as getting going, freer, easier, bearable, loosened, more mobile, stiffness subsides, and stand up straight. The majority of patients did not like asking for help and try to cope on their own, so some set their alarms to wake up earlier to allow more time in the mornings. Labour-intensive activities were sometimes postponed until later in the day.

**Respondents to the quantitative survey**

The survey was completed during the first half of 2010. A total of 750 patients completed the questionnaire (100 from each of France, Italy, Spain, and the UK; 50 from each of the other countries). The gender and age distribution of respondents reflected the recruitment targets (Table 1). The majority of respondents were female (73%) and had established RA of more than 2 years duration (68%). The majority of patients (86%) had had RA for 10 years or less, but the very prolonged duration experienced by a minority of respondents resulted in a mean time since diagnosis of 9.1 years.

A total of 518 rheumatologists completed the survey (77 from France, 76 from Italy, 75 from each of Spain and the UK, 50 from Poland, 30 from each of Belgium, Denmark, the Netherlands, and Sweden, 25 from Norway, and 20 from Finland). Characteristics of the respondents are summarized in Table 2. Approximately three-quarters of the respondents (73%) worked in public hospitals and half of the respondents (51%) spent more than 80% of their time directly on patient care.

**Perceived duration and severity of impaired morning function**

The mean duration of morning stiffness and pain was 83 min according to patients, slightly longer than that estimated by rheumatologists (70 min). Impaired morning function lasting more than 30 min/day was reported by 75% of patients, with 74% of rheumatologists estimating this duration for their patients (Figure 1). On a scale of 0 (no morning stiffness) to 10 (severe morning stiffness), 23% of patients rated their symptoms as severe (score of 8–10), 70% as moderate (4–7), and 7% as mild (1–3). The mean score was 6.2.

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<th>Table 1. Characteristics of patients (n=750) included in the survey.</th>
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<td>Female, n (%)</td>
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<td>Age distribution, n (%)</td>
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<td>18–45 years</td>
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<td>Duration of RA, n (%)</td>
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<td>Mean duration of RA (years)</td>
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<table>
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<th>Table 2. Characteristics of rheumatologists (n=518) included in the survey.</th>
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<td>&gt; 80% of time spent in direct patient care, n (%)</td>
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<td>Seeing more than 50 patients/month with RA, n (%)</td>
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<td>Main place of work (&gt; 50% of time), n (%)</td>
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<td>Length of time in practice, n (%)</td>
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The majority of patients (82%) reported that impaired morning function had a significant impact on their quality of life. Three out of five respondents (61% of the 732 patients giving a view) said that impaired morning function controlled their life. An impact on others was also noted, with nearly half the respondents (47% of 723 patients) saying that impaired morning function affected their relationships and over a third (39% of 734 patients) saying it made them feel a burden to others.

Impact on activities and emotional state

Patients were asked about their ability to carry out normal activities associated with starting the day while experiencing impaired morning function. Only around a third of the patients surveyed were able to get out of bed, take a shower or bath, dry themselves, get dressed, and make breakfast in the way they had always done (Figure 2). Brushing teeth was an activity that proportionately more patients (50%) were still able to do unimpaired.

Patients reporting that their activities were affected by impaired morning function were asked about the resulting emotional impact. More than half the respondents (58%) reported that the difficulty in doing things in the morning made them feel frustrated and a third (32%) felt angry; others reported feeling emotionally drained (27%) or defeated (14%).

Morning symptoms of pain and stiffness, and the consequent inability to function, caused distress for patients. Slightly more patients reported that distress was due to morning pain (68%) than difficulty in carrying out activities (65%) and morning stiffness (63%). However, inability to function was noted as the most distressing effect by more patients (35%), compared with pain (29%) and morning stiffness (25%).

Impact on work

Of the 750 patients taking part in the survey, 37% were in paid employment, 23% were retired, 13% had retired early due to ill health, 7% were on sick leave from work, and 20% had other work status (e.g. homemaker, unemployed, student). Almost one in five patients (18%) was unable to work (i.e. retired early, on sick leave, or unemployed) because of RA. Three-quarters (74%) of those retired early, on sick leave, or unemployed attributed the cause to RA.
Among the 274 patients in paid employment, 73% reported an impact of impaired morning function on their job. Among the working patients, 47% were sometimes unable to work because of problems with functioning in the morning and 26% reported a slowing of career progression (Figure 3). Morning impairment resulted in time off work during the previous 6 months for 40% of working respondents, with a mean of 4.5 working days lost per employed person. Among those losing time from work, 45% missed 10 or more working days during the previous 6 months.

Discussion

This survey, conducted in 11 European countries among patients with RA who experienced impairment of morning function at least 3 days/week, shows that morning symptoms have a significant adverse impact on the lives and well-being of patients with RA. Most of the patients surveyed (92%) described the impairment in morning function as moderate or severe. For 82% of patients, impaired morning function has a significant impact on their quality of life, causing frustration and distress. Rheumatologists were aware that impaired morning function affects their patients. The estimates of morning stiffness duration were similar among rheumatologists and patients experiencing the problem, and there was also close agreement between both groups of respondents about the impact on quality of life.

Although it provides a useful insight, the study has some limitations. This study does not provide data on the prevalence of early morning stiffness in populations of patients with RA, but merely assesses the severity of this problem and its impact among those who suffer from it. Patients recruited to the study were all experiencing impaired morning function at least 3 days/week, so the findings cannot be extrapolated to an unselected population of patients with RA, some of whom do not experience morning symptoms at a given time. Patients recruited to the study were all experiencing impaired morning function at least 3 days/week, so the findings cannot be extrapolated to an unselected population of patients with RA [Disease Activity Score (DAS) ≤ 3.2] experienced morning stiffness to some extent. Thus it is likely that the findings of this survey apply to a considerable proportion of patients with RA.

Other studies have examined the impact of RA (but not specifically morning symptoms) on quality of life. Indeed, RA has been reported to have the highest adverse impact on health-related quality of life among common chronic diseases because of the limitations of physical function, pain, fatigue, impact on work, and participation in activities (6). The results of this survey suggest that morning symptoms contribute greatly to this adverse impact on quality of life. The inability to carry out normal activities associated with starting the day was shown in this survey to have a negative emotional impact. This result is consistent with the finding that loss of ability to carry out daily functions is associated with the onset of depressive symptoms (7). It has recently been suggested that, in addition to disease activity, functional ability and quality of life should be assessed routinely in patients with RA (8).

The survey suggests a profound impact of morning symptoms on patients’ ability to work. Only a minority of patients surveyed (37%) were in paid employment, despite the majority (81%) being of working age (i.e. ≤ 65 years). Most working patients (73%) reported that impaired ability to function in the morning had a detrimental effect on their work. Three-quarters of those who were retired early due to ill health, on sick leave, or unemployed reported that this was due to RA. In Germany, it has been reported that retirement from work within 3 years of diagnosis is associated with severe morning stiffness (5). Such loss of paid work has been shown to be associated with reduced quality of life (9). It is clearly important, for both economic and emotional reasons, to ensure that patients with RA receive optimal treatment to control both troublesome morning symptoms and prevent disease progression so they can continue to play an active part in the workforce.

In conclusion, the survey shows that impaired morning function has considerable impact on patients, reducing their ability to carry out activities associated with starting the day, and adversely affecting working life and emotional status. Rheumatologists’ perceptions of the duration and impact of impaired morning function correspond closely with patients’ perceptions.
Acknowledgements

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References


Appendix 1: Questions included in the questionnaire for patients

Q54 For approximately how long have you suffered from rheumatoid arthritis? [Base: all respondents]
Q56 How often do you experience impaired morning function? [Base: all respondents]
Q57 Age [Base: all respondents]
Q58 Gender [Base: all respondents]
Q59 What is your current employment status? [Base: all respondents]
Q52 Are you unemployed/early retired/on sick leave because of your rheumatoid arthritis? [Base: respondents who are unemployed, on sick leave or retired early]
Q53 Which healthcare professionals do you see about your rheumatoid arthritis? [Base: all respondents]
Q57a ‘Impaired morning function has a significant impact on my quality of life’. To what extent do you agree with this statement? [Base: all respondents]
Q57b ‘Impaired morning function has a significant impact on my job’. To what extent do you agree with this statement? [Base: all respondents who work]
Q58 Does your rheumatoid arthritis and its associated symptoms affect your sleep, resulting in a loss of sleep? [Base: all respondents]
Q57 ‘Loss of sleep caused by my rheumatoid arthritis and its associated symptoms has a significant impact on my quality of life’. To what extent do you agree with this statement? [Base: all those who lose sleep due to RA/RA symptoms]
Q51a Typically, how long do the periods of impaired morning function (pain and stiffness) last in the morning? [Base: all respondents]
Q51b How would you rate the severity of your morning stiffness on a typical morning? [Base: all respondents]
Q51c What, if any, actions do you take to help relieve you from your impaired morning function? [Base: all respondents]
Q51d How, if at all, effective is the medication you are currently taking for relieving your symptoms of impaired morning function? [Base: all those who take medication for their impaired morning function]
Q51e Do you set an alarm to wake up earlier in the morning than you need to get up, to take your medication for impaired morning function (pain and stiffness)? [Base: all those who take medication for their impaired morning function]
Q51f How many hours do you set this alarm before you actually have to get up? [Base: all those who set an alarm to wake up early to take medication]
Q51g Please think about the impaired morning function (pain and stiffness) associated with your rheumatoid arthritis and indicate how much you agree or disagree with each of the following statements [Base: all respondents]:
   My impaired morning function controls my life
   My impaired morning function affects my relationships
   I feel like a burden to others because of my impaired morning function
   My impaired morning function is difficult to manage
Q51h Did your rheumatologist mention impaired morning function specifically when you were diagnosed with RA? [Base: all those who see a rheumatologist]
Q51i Has your rheumatologist ever asked if you suffer from impaired morning function? [Base: all those who see a rheumatologist]
Q51j How often does your rheumatologist ask you about your impaired morning function? [Base: all those asked by rheumatologist if they ever suffer from impaired morning function]
Q51k Have you talked to your rheumatologist about your impaired morning function? [Base: all those who see a rheumatologist]
Q51l How often have you spoken to your rheumatologist about your impaired morning function? [Base: all those who have spoken to their rheumatologist about their impaired morning function]
Q51m Why have you not/not often spoken to your rheumatologist about your impaired morning function? [Base: all those who do not speak often/at all to their rheumatologist about their impaired morning function]
Q51n Would you like to talk to your rheumatologist about your impaired morning function? [Base: all those who have not spoken to their rheumatologist about their impaired morning function]

Appendix 2: Questions included in the questionnaire for healthcare professionals

QS4 For approximately how long have you suffered from rheumatoid arthritis? [Base: all respondents]
QS6 How often do you experience impaired morning function? [Base: all respondents]
QS7 Age [Base: all respondents]
QS8 Gender [Base: all respondents]
QS10a Typically, how long do the periods of impaired morning function (pain and stiffness) last in the morning? [Base: all respondents]
QS10b How would you rate the severity of your morning stiffness on a typical morning? [Base: all respondents]
QS11 What, if any, actions do you take to help relieve you from your impaired morning function? [Base: all respondents]
QS12 How, if at all, effective is the medication you are currently taking for relieving your symptoms of impaired morning function? [Base: all those who take medication for their impaired morning function]
QS13 Do you set an alarm to wake up earlier in the morning than you need to get up, to take your medication for impaired morning function (pain and stiffness)? [Base: all those who take medication for their impaired morning function]
QS14 How many hours do you set this alarm before you actually have to get up? [Base: all those who set an alarm to wake up early to take medication]
QS15 Please think about the impaired morning function (pain and stiffness) associated with your rheumatoid arthritis and indicate how much you agree or disagree with each of the following statements [Base: all respondents]:
   My impaired morning function controls my life
   My impaired morning function affects my relationships
   I feel like a burden to others because of my impaired morning function
   My impaired morning function is difficult to manage
QS17 Did your rheumatologist mention impaired morning function specifically when you were diagnosed with RA? [Base: all those who see a rheumatologist]
QS18 Has your rheumatologist ever asked if you suffer from impaired morning function? [Base: all those who see a rheumatologist]
QS19 How often does your rheumatologist ask you about your impaired morning function? [Base: all those asked by rheumatologist if they ever suffer from impaired morning function]
QS20 Have you talked to your rheumatologist about your impaired morning function? [Base: all those who see a rheumatologist]
QS21 How often have you spoken to your rheumatologist about your impaired morning function? [Base: all those who have spoken to their rheumatologist about their impaired morning function]
QS22 Why have you not/not often spoken to your rheumatologist about your impaired morning function? [Base: all those who do not speak often/at all to their rheumatologist about their impaired morning function]
QS23 Would you like to talk to your rheumatologist about your impaired morning function? [Base: all those who have not spoken to their rheumatologist about their impaired morning function]
Impact of morning function on the well-being of RA patients

Q24 What, if anything, did your rheumatologist do or say about your impaired morning function? [Base: all those who have discussed impaired morning function with their rheumatologist, regardless of who took the initiative]

Q26 I am now going to read out a list of activities that you might do in the morning while you are still suffering from impaired morning function. For each activity, please tell me how you do the activity. [Base: all respondents]
  - Getting out of bed
  - Brushing teeth
  - Getting into the bath/shower
  - Drying body/hair
  - Dressing
  - Making breakfast

Q27 How does it make you feel emotionally when you can’t do things/find it more difficult to do things due to your impaired morning function? [Base: respondents who have difficulties with daily activities]

Q29 Do any of the following cause you distress in the morning? [Base: all respondents]
  - The fact you can’t do things
  - The pain you experience as a result of the stiffness
  - The morning stiffness itself

Q29a Please could you rank from the one that causes most distress to the least in terms of the relative distress each causes you in the morning? [Base: all respondents who selected more than one distress statement]

Q30 Have you ever found yourself in any of the following circumstances as a result of your impaired morning function? [Base: respondents who work]
  - Been unable to work
  - Career progression has slowed down
  - Had to change profession
  - Been made redundant
  - Forced by your employer to leave your job

Q32 In the last 6 months how many days, if any, have you missed from work because of your impaired morning function?

Appendix 2: Questions included in the questionnaire for rheumatologists

S1 How many years have you been in practice since completing your medical training? [Base: all respondents]
S5 What percentage of your time is spent in direct patient care? [Base: all respondents]
S6 Where do you spend the majority (i.e. more than 50%) of your time working? [Base: all respondents]
Q11 How many of your RA patients suffer from impaired morning function? [Base: all respondents]
Q12 In your opinion, how long on average does impaired morning function last in the morning? [Base: all respondents with RA patients who experience impaired morning function]
Q13 'Impaired morning function has a significant impact on RA patients’ quality of life’. To what extent do you agree with this statement? [Base: all respondents with RA patients who experience impaired morning function]
Q14 Do any of your patients raise the issue of impaired morning function with you? [Base: all respondents]
Q15 Of the RA patients you see in a typical month, how many have complained about impaired morning function? [Base: those who have patients that ask about morning function]
Q17 Do you tell your patients about impaired morning function when they are first diagnosed with RA? [Base: all respondents]
Q18 Do you ask your RA patients whether they are affected by impaired morning function? [Base: all respondents]
Q19 Why not? [Base: those who do not ask their patients about morning function]
Q20 How often do you ask patients about their impaired morning function? [Base: those who ask their patients about morning function]
Q22 To what extent do you agree or disagree with the following statements? [Base: all respondents]
  - Impaired morning function should be treated specifically
  - Current treatment options do not address impaired morning function specifically
  - Current treatment options for impaired morning function are ineffective
  - Patients should accept that impaired morning function is part of their condition
  - There is a need for new treatments to treat impaired morning function

Q23 What actions do you take/advice do you give patients that suffer from impaired morning function? [Base: all respondents]
Q24 Do you specifically treat impaired morning function? [Base: all respondents]
Q25 What percentage of your patients affected by impaired morning function is currently taking prescription medication specifically for it? [Base: those that specifically treat impaired morning function]
Q26 What medications do you prescribe specifically for impaired morning function? [Base: those prescribing a treatment specifically for impaired morning function]
Q27 How effective do you perceive medication for impaired morning function to be? [Base: those prescribing a treatment specifically for impaired morning function]