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## RESEARCH PAPER

# ‘Walking like John Wayne’: open-format diaries of people with knee pain and disability

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**Objective:** To describe older people’s everyday experience and context of living with knee pain and disability, and to explore the potential of open-format diaries in accessing these experiences.

**Methods:** This was a diary study, embedded in a larger mixed-method study. Ten people who participated in a qualitative interview study volunteered to keep an open-format diary over a period of 1 week.

**Results:** Diaries provided current and historical details about people’s lives and their health. The diaries set these experiences within the context of daily life, and combined description with reflection. Themes covered included: causes of pain, symptoms and treatments, consultations, and co-morbidity.

**Discussion:** Open-format diaries allow insights into the complex and contextual experience of pain and disability, and because of the contemporaneous detail, can be helpful to clinicians’ holistic understanding of the impact of knee pain on people’s quality of life. This method provides descriptive material that complements survey and qualitative interview data.

**Keywords:** Diary study, Knee pain, Osteoarthritis, Qualitative research, Quality of life

## INTRODUCTION

Musculoskeletal problems are very common. The size of the burden and their relevance to public health are now well documented,<sup>1–3</sup> and previous epidemiological studies have also shown their impact on quality of life.<sup>4</sup> Osteoarthritis is the most common type of musculoskeletal condition, and in particular affects older people. Knee pain in older adults is thus a major cause of disability,<sup>5–8</sup> but little is known about the day-to-day experience of people living with this condition. Sanders *et al.*<sup>9</sup> have investigated the significance and consequences of painful and disabled joints, and found that older people portrayed symptoms as a normal part of their biography but also talked about how symptoms were highly disruptive to everyday life.

The aims of the current study were: first, to explore the potential of open-format diaries to provide insight into the personal experience of living with knee pain; and second, to focus on the everyday processes that people are engaged in and explore links with the social context.<sup>10,11</sup>

The purpose of a diary study is to capture events close to when they occur and to record routine and everyday life.<sup>12</sup> Elliot has argued that diaries, as an important expression of auto/biography, have the potential to bring to the fore ‘muted’ accounts of health and illness. In her research, individuals have been able to construct accounts of their health that may be at odds with dominant clinical or cultural discourse. Diaries can also provide a way of gaining access to what actually happens in everyday life and to the subjective meanings attributed to such events,<sup>13</sup> and it has been suggested that research into quality of life should focus on the study of day-to-day life and not just on retrospective in-depth interviewing.<sup>14</sup>

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Diaries can be considered as a form of oral history and auto/biography that reveal how knowledge of everyday life is constructed, and how accounts of (remembering) the past are created.<sup>15</sup>

## METHODS

### Participants

In March 2000, we mailed a postal questionnaire to all 8995 adults aged 50 years and over who were registered with three general practices in North Staffordshire. The survey was about general health, knee pain and disability, and related healthcare use.<sup>8</sup> Six thousand seven hundred and ninety-two people (77% adjusted) responded to the survey; 5784 of these were still active in 2003 when we mailed a follow-up questionnaire. Four thousand three hundred and seventeen responded to the follow-up survey, and 58% of these gave consent for further contact. We categorized survey responders into four groups according to whether or not they had consulted their general practitioner in the last 12 months, chronicity of knee pain (chronic=more than 3 months, or non-chronic=less than 3 months), age (over or under 75 years), and gender. We therefore ended up with 16 groups.

We randomly sampled four responders from each group and wrote to invite them to take part in a qualitative interview, focusing on their experiences of knee pain and disability. Twenty-two people agreed to be interviewed (17 selected from this knee survey and five from a parallel joint pain study). On completion of the interview, the interviewer then asked whether the individual would be willing to complete an open diary for a period of 1 week. If patients consented, they were given a notepad, a pen, and a stamped address envelope in which to return the diary after a week. Ten people volunteered to keep a diary within the period January–March 2004. Each phase of the study (questionnaires, interviews and

diaries) was approved by the North Staffordshire Research Ethics Committee. In this paper, we report on the diary element of the KNEST study and how this enhances the findings from the linked quantitative study (North Staffordshire Local Research Ethics Committee project 02/79).

### Data Analysis

The diaries were analysed in two ways. First, all the diaries were coded, focusing primarily on the views and interpretations of the diarists, augmented by the themes and thoughts that researchers drew from the texts. The analysis was built from the themes that emerged from the coding and categorization of data, and was based upon the approach used by Strauss and Corbin.<sup>16</sup> Second, where diaries contained detailed stories, we used an analytical approach that was informed by narrative theories about the construction of illness stories.<sup>17</sup> The way in which the diarists wrote about their experiences provided insights into their construction of self and the ways in which they conveyed this to others, including healthcare professionals. Maintaining the integrity of their narrative emphasized their logic and social context. Narratives tend to exhibit a degree of interpretation and reflexivity, and often contain elements of moral tales. This is particularly relevant with regard to illness narratives, where the narrative form is used to shape lived experiences in order to give them meaning and significance.<sup>17</sup>

## RESULTS

The ten diaries varied in length, with two diaries (Mary and Joyce) providing both current and historical details, and eight diaries focusing on symptoms and treatments. This degree of variation in both description and reflection has been found in other studies.<sup>18</sup> The main themes illustrate the creation of personal narratives that contextually reflect the experience of living with knee pain.

### The Cause of Pain and its Meaning

One of the diarists (Joyce) wrote a detailed account of her current pain, and the history and development of her pain. Three major accidents that she had when working as a carer were described in great detail; each of them caused her to suffer considerable damage and incremental pain. The dangers of working in other people's homes were graphically illustrated, as many of her clients appeared not to have the means or ability to maintain their houses to a safe standard. The first incident happened in 1985:

*I was coming down the stairs of a client, but unfortunately for me, the carpet on the second top step came away from the stairs. There were handrails both sides. My left hand carried the electric small sweeper, my right hand was on the hand rail, but my feet went up in the air, and down I was falling.*

After the fall, she took some painkillers, and sat down for a while before telling her supervisor to record the fall in the accident book. Her supervisor suggested that she went home, but Joyce said, 'I told her I was just shook up, and I would carry on to my next last call for the day'. Despite advice from her employers to go to the doctor, and to take time off, she carried on working, playing down the extent of her injuries and pain. In the unfolding of the stories of her three work accidents, she clearly made the links between the risks inherent in her occupation and the causes of her accumulated pain and disability. At the same time, acknowledging the extent of her health problems was difficult because of her own perception that her role as a paid carer should not be adversely affected. This also appeared to influence her interpretation of accidents at work as inevitable and acceptable. The meaning given to her suffering could be taken as an integral part of a 'hard-earned life'.<sup>11</sup>

Many diaries described specific activities or circumstances that led to pain. The most commonly mentioned activities were shopping (walking and carrying), cleaning (including washing cars), going up and down stairs, and moving from one position

to another (from sitting to standing). Although there is a lack of strong evidence in this area,<sup>19,20</sup> cold and dampness also figure in the accounts, and this quote graphically illustrates the effect:

*5th February. Dull aches and stiffness in my knees all weekend, walking like John Wayne. Possibly due to the cold. (Shirley)*

The connection between pain and ageing was alluded to in most diaries, and the following account demonstrates this:

*Friday, 20th February. Had some pain and stiffness in my knees later in the day when squatting/stooping down for a short while looking in a low cupboard — pain was around the knee joint. This faded away when I stood up and flexed the joint — getting erect was a struggle. I find this frustrating at times, but accept it as one of the disadvantages of growing old. (Peter)*

The diarist clearly explains the emergence of pain within his daily routine, and the impact it has on his mobility. At the same time, he adds that it is part of 'normal ageing' and therefore he feels that he must accept the pain and its consequences. In this account, the meaning of pain cannot be separated from the meaning of old age.

### Knee Pain in the Context of Co-morbidity

As knee pain tends to predominantly affect older people, co-morbidity is more likely. In the diaries, co-morbidity took two forms: first, people mentioned problems other than musculoskeletal pain; and second, pain elsewhere featured in all the diaries. The other health problems revealed included angina, diabetes and respiratory disease. The impact of knee pain on people's daily life was considerable, but the interplay with other diseases appeared to exacerbate adverse effects:

*Wednesday, 3rd March. After breakfast took the dog a walk. As we live on a bank going isn't too bad, but coming back is worse. I think it is going up the bank that the feet are at an awkward sloping angle. I missed having a mid-morning drink and biscuit. About 11.30 I started to go wobbly and weak kneed. Sat down and ate three digestive low sugar digestives. (Mary)*

The above excerpt explained that walking up a bank was difficult, but that being diabetic added an extra dimension. Becoming weak in the knees appeared to be a combination of the physical exertion and the dropping blood sugar levels (hence the need to eat biscuits), and careful management of both problems was a key feature in this diary.

Nearly every diary specified pain in other parts of the body, in particular legs, feet, shoulders, arms, back and neck. Certain pain locations may appear to be logically linked to knee pain, in particular lower limb pain, while other types of pain are not apparently associated. The following diarist lists a range of problems:

*Saturday 14th February. 5.30 a.m.: awoke from sleep, numbness in hands, shook hands relieved numbness. 6.30 a.m.: got up, went downstairs, felt discomfort in left knee going down the stairs, also going up. No problems during course of the day with left knee. However, intermittent ringing in right ear during the course of the day. 11.30 p.m. went to bed, felt discomfort going upstairs. (John)*

While the account does not explicitly connect the different health problems with each other, the mention on the same page, and the use of the word 'however' between the knee pain and the ear problem, are intriguing. The diarist adds a PS, in which he lists further health problems, giving the impression of a person experiencing widespread pain. At the same time, he ends the page with 'how I feel about the pain is this: there are others worse off than me, much worse off'. Like Mary, this person lived with a complex array of problems, yet the emphasis in his account — and most of the others — was on managing the pain within the broader context of living with co-morbidity. The fact that people adopted this broader perspective could be due to the holistic nature of the study, namely eliciting people's account of their daily life. At the same time, the reality of this life meant dealing with a range of health problems of which pain was an integral part. Furthermore, this approach also reflected previous research in older adults,

where accepting one's lot as a coping strategy and having a positive outlook were identified as contributing to the maintenance of quality of life.<sup>21</sup>

### Consulting for Knee Pain

The interview sample was designed to capture consulters and non-consulters, and the diary study ended up with a 50/50 split. Chronicity appeared to be the determining factor for consultation in the diary sample. However, none of the diaries described consultations with general practitioners or other health professionals. People with chronic knee pain appeared to adopt self-care as a key strategy for coping, which could explain the lack of consultation reports. Thorne *et al.*<sup>22</sup> argue that in the everyday management of their illness people become experts in their experience, and weigh up professional advice against this experiential knowledge. Thus, self-care decisions are taken within the context of their life, the disease trajectory, and their own desires and aspirations, and are not just a matter of accepting and implementing professional advice.

Carol recorded her daily intake of pain-killers, Mary mentioned exercises, diarists Barbara and Shirley tried to walk, and Joyce mentioned exercise and her attitude:

*I do a little light exercise every morning. Even if I don't want to, I make myself. I will not give in to my aches and pains. I'm a survivor. I will **not** give in.*

The people who had non-chronic knee pain all reported co-morbidity, and generally those other health problems were more important than the knee pain. Even though consultations were not explicitly mentioned, the seriousness of their ill-health implied that medical help was sought — even though this was not related to knee pain. For example, Keith reported:

*Used Pro-Step exercises gently for approximately two minutes. Cannot do a lot with this as I become very breathless at least exertion as I work on one lung and suffer from heart failure.*

This gentleman relied on his wife, who gave him massages and reflexology treatment to

cope with his knee and other osteoarthritic pains instead of consulting healthcare professionals. His self-management, therefore, included his wife, who took a major part in improving his wellbeing.

## CONCLUSION

The diarists' biographies illuminate the impact of knee pain on daily life, and do so in contemporary detail that may not be captured in a qualitative interview alone. They provide a patient-centred methodology, enabling the subject to write freely on the issues of importance to them within the context of their everyday life, which are not always accessed using other methods.<sup>18</sup> The insights gained from diary research can be helpful to clinicians' holistic understanding of the impact of knee pain on people's quality of life. Coping and self-management strategies were revealed, and individuals' expectations of suffering pain and disability and how these are related to expectations about what life brings have been revealed. One striking feature of all of the diaries was the co-occurrence, adaptation to and personal management of musculoskeletal pain and other health problems. While health professionals were consulted, the desire to cope with ill-health emerged as a strong feature in the accounts, and self-management was a prominent feature.

This diary study has some limitations that may be related to literacy skills, physical difficulties with writing, varying narrative depth and the relatively short period of diary-keeping. As the diarists were self-selected, they might have been the type of people who were more self-reliant and managed their own care. In comparison to in-depth interviews, the diaries did not allow for probing, and hampered the interpretation of certain statements (for example, John mentioned ear problems and knee pain in the same excerpt).

Nevertheless, insights gained from open-format diaries are relevant to clinicians and

researchers, as they portray the real-life experiences and impact of living with knee pain and disability. The context of people's social situation, their beliefs about illness and the complexity of co-morbidity present additional dimensions to allow clinicians a broader view of patients and also enable the diarists to present their own priorities.<sup>18</sup> Understanding patients' journeys<sup>23</sup> by listening closely to their individual voices might empower patients and assist health professionals in aligning interventions more closely to the lived experience of pain. For health services researchers, using open-format diary material alongside interview and questionnaire data enhances the understanding of quality of life in older adults, because leaving people free to write their own accounts presents specific advantages: capturing the lived experience of ill-health and disability and the way in which health and coping strategies change over time provides a unique opportunity to bring to the fore the 'taken for granted'. Unless better understanding about the hidden aspects of living with pain and disability is gained, support and health advice may not be fully effective.

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