



Understanding the needs of consumers

A systematic scoping review of consumers' perceived needs of health information, health services and other non-medical services

A RESEARCH PROJECT PLAIN LANGUAGE SUMMARY

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Project timeline: 2014–2016

Background

Musculoskeletal conditions - or conditions that affect muscles, bones and joints - are a major public health burden. In 2012, it was estimated that there were 6.1 million cases of arthritis and other musculoskeletal conditions in Australia (26.9% of the population). This included 2.9 million people with back problems, 1.9 million people with osteoarthritis, 0.8 million people with osteoporosis and 0.5 million people with rheumatoid arthritis¹.

These conditions can significantly affect the quality for people living with them. In many cases, the best way to manage these conditions is through a team approach involving the consumer and their healthcare team, as appropriate to the condition (general practitioners, specialists, physiotherapists, occupational therapists, pharmacists etc).

For this team approach to work effectively and to actively manage their condition, the consumer needs to play a central role. Their aims and health outcomes should be in line with those of their healthcare team. In order to align these aims, it's necessary to understand what the consumer sees their own healthcare needs to be. It's also important to understand that their perspective of need may be different to the health professionals' perception of the situation.

The aim of this research project was to identify existing information relating to consumers' needs specifically focusing on:

- health information
- health services
- other non-medical services (services that affect consumers' lives but are not directly related to health care)..

The project

Researchers conducted a systematic scoping review on the major musculoskeletal conditions (inflammatory arthritis - rheumatoid arthritis and ankylosing spondylitis; osteoarthritis; back pain; neck pain and osteoporosis/osteopenia).

Systematic scoping reviews are used to make sense of large bodies of information related to a specific question. Researchers use systematic methods to identify, select and critically appraise relevant research. They then extract and analyse data from the studies in order to answer the research question.

In this review, literature was searched relevant to each of the musculoskeletal conditions to identify reported consumers' perceived needs specifically relating to health information, health services and other non-medical services. The relevant studies were identified and information regarding each area of need was combined, discussed and summarised to draw out themes.

Findings

Overall, high quality evidence from the consumer perspective was lacking. Despite this, the findings across the different musculoskeletal conditions tended to be complementary and consistent. This suggests there is a reasonable web of evidence from which conclusions can be made.

Consumers' perceived needs regarding health information

Consumers' wanted high quality, accurate information with simple explanations of their condition, delivered in a supportive and non-judgemental fashion. They looked for information in order to:

- gain control of their condition
- improve function
- understand how their condition would progress
- take action to improve their health state and quality of life.

They wanted general information regarding their condition, its management, and strategies to manage flares. Consumers also wanted information regarding lifestyle factors - such as diet and exercise - to help manage their condition.

Consumers identified a need for health information to be provided using different types of media (e.g. print, audio-visual, online and social media). This suggests that multimedia options may be an important addition to face-to-face communication. Support from peers in sharing information was also identified as important.

This review highlights that there is much to learn about the role of different forms of non-personalised information delivery. This includes understanding the consumers' preferences for different modes of delivery and how effective these are.

The various forms of information delivery may be able to be used to supplement usual care and reduce pressure on the healthcare system. Non-medical personnel may be involved to help provide health information to consumers. Having a better understanding of the usefulness of different forms of media will be helpful in achieving better health outcomes.

Consumers' perceived needs regarding health services

Health services needs identified in the studies tended to be similar for consumers across the conditions examined in this review.

Consumers saw the benefit of medications, but were concerned about the potential for side effects and addiction. They were also wary of procedural interventions such as surgery. Those with back and neck pain felt a strong need for an accurate diagnosis in order to legitimise or to 'prove' that there was a reason for their pain.

Allied health and complementary medicine were seen to complement medical therapy, and to provide relief of symptoms. They were not seen to be a cure for their condition.

Individualised information and exercise programs were preferred to group and 'off the shelf' treatments.

Consumers preferred healthcare providers who:

- take a thorough, holistic approach to health care
- have good communication skills
- allow consumers to take an active role in their own management
- are empathetic and understanding.

Consumers wanted to receive clear and consistent information, including an explanation of why they have pain. They also wanted care to be delivered at a convenient time and place.

The main barriers to healthcare services were seen to be cost, followed by access issues (related to waiting times for appointments and referrals) and the convenience of the healthcare provider's location.

Factors such as lack of time, transport issues and cost were identified as impacting on consumers ability to comply with allied health programs. Social obligation, particularly for women, was seen as a barrier to looking after their own health.

Some condition-specific health information needs were also identified. In particular, those with back and neck pain expressed a strong need for a definite diagnosis. They believed this was necessary to legitimise their pain and to develop a clear treatment plan.

Consumers' perceived needs regarding other non-medical services

This review has identified that people with musculoskeletal conditions also have a number of common needs outside health care. They require practical help within the home to enable them to look after themselves. This task often fell to family members.

Environmental factors impacted on their ability to function both inside and outside the home and in the work environment. Consumers appreciated peer support and identified the need for social outlets. Loss of social connections impacted on their sense of wellbeing. This was worsened by loss of employment.

The workplace was important in terms of identity, financial security and social connections. Maintaining employment was a high priority for consumers with musculoskeletal conditions. Consumers also wanted easier access to safe transport and disability parking permits.

Conclusions

This review studied consumers' perceived health information, health services and other non-medical service needs as they related to living with inflammatory arthritis (rheumatoid arthritis, ankylosing spondylitis), osteoarthritis, back pain, neck pain and osteoporosis. In particular, consumers sought legitimacy for persistent pain and a diagnosis to direct appropriate care. Given that a large proportion of musculoskeletal pain cannot be reliably associated with physical or structural characteristics, prioritising the understanding of persistent pain among consumers is needed.

Although the management of these conditions requires understanding consumers' perceived needs, there is limited data in the literature relating to their perceived needs. Specifically, not all questions are addressed in each of the targeted conditions. Therefore, if a need hasn't been identified in this review it does not mean that the need doesn't exist, unless it has been directly addressed by identified studies. Nevertheless, there were many common areas of need across these conditions, with few conflicting results.

There are a number of significant gaps identified in what is known about consumers' perceived needs that need to be addressed by further research. Filling these gaps will help to better identify and characterise consumers' needs relating to musculoskeletal conditions. This may enable healthcare providers and other stakeholders to better target strategies to obtain better musculoskeletal health outcomes.

Recommendations

Based on the findings of the systematic review, three levels of recommendations for action are proposed:

- System-level recommendations
- Health service-level recommendations
- Healthcare provider-level recommendations for action.

Recommendations are also proposed for ongoing research recommendations.

[Click here to access the full report](#) if you would like to read these recommendations.

How we can help

Call our MSK Help Line and speak to our nurses. Phone 1800 263 265 or email helpline@msk.org.au.

We can help you find out more about:

- arthritis and musculoskeletal conditions
- ways to live well with these conditions
- managing your pain
- upcoming webinars, seminars and other events.

¹ Arthritis and Osteoporosis Victoria. A problem worth solving. Elsternwick: Arthritis and Osteoporosis Victoria, 2013.