Domains of quality of life affecting elderly patients with hand osteoarthritis: a qualitative study in the Asian perspective

Julian THUMBOO,1,2,3 Li WU2 and Ying Ying LEUNG1,2

1Department of Rheumatology & Immunology, Singapore General Hospital, 2Duke-NUS Medical School, and 3Yong Loo Lin School of Medicine, National University of Singapore, Singapore, Singapore

Abstract

Objectives: Hand osteoarthritis (HOA) is common but little is known about how HOA has impact on disability and quality of life (QoL). We aim to identify important domains of concern among participants suffering from symptomatic HOA in Singapore, representing an Asian socio-cultural context.

Methods: A qualitative study using a focus group technique was performed. We ran focus groups stratified by gender, ethnicity and language. Two independent, trained analysts identified relevant categories and assigned codes to text segments through open coding, with discrepancies resolved through consensus. The final lists of domains and subthemes descriptive of QoL were then compared to the following commonly used HOA specific instruments: Functional Index for Hand Osteoarthritis (FIHOA), Score for Assessment and quantification of Chronic Rheumatic Affections of the Hand (SACRAH), Australian/Canadian Hand Osteoarthritis Index (AUS-CAN); and Health Assessment Questionnaire (HAQ).

Results: Twenty-six patients (23 women, three men; 24 Chinese and two Malay; mean ± SD age 62.9 ± 7.5 years) with symptomatic HOA according to the American College of Rheumatology Classification Criteria participated in seven focus groups. Two and five focus groups were conducted in Chinese and English, respectively. The qualitative analysis revealed pain, stiffness and functional disability as the main domains. However, psychological consequences, aesthetic concerns, participation in leisure activities, participation in family roles were important concepts from the focus groups which were not covered by existing instruments. Impact on work productivity by HOA and the unmet health care need is revealed.

Conclusion: The domains of concepts important to people with HOA in an Asian socio-cultural context are not fully represented in the most commonly used instruments. Further studies on the selection of main domains relevant to HOA patients are necessary.

Key words: hand osteoarthritis, qualitative study, quality of life.

INTRODUCTION

Hand osteoarthritis (HOA) is a common disease. The prevalence of radiographic HOA ranges 29–76%1,2. Symptomatic HOA was reported in 6.1–9.7% of the elderly population,3 incurring pain, disability and impaired quality of life (QoL). Preliminary studies suggest the burden of HOA is similar to rheumatoid arthritis (RA),4 but the true impact of HOA to disability and QoL has not been well studied.5,6 This is partly because it has not been clear how HOA is affecting patients from their own perspectives, and therefore it is not clear how QoL in these patients should be measured.

Correspondence: Dr Ying-Ying Leung, Department of Rheumatology and Immunology, Singapore General Hospital, The Academia, level 4, 20 College Road, Singapore 169856, Singapore. Email: katyccc@hotmail.com

© 2016 The Authors. International Journal of Rheumatic Diseases published by Asia Pacific League of Associations for Rheumatology and John Wiley & Sons Australia, Ltd.
This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.
Although there are some existing QoL instruments used in the literature, these instruments were developed from a list of concepts selected by professionals, which did not align with the US Food and Drug Administration (FDA) recommendation of using inputs elicited from patients. The World Health Organization (WHO) defines QoL as the ‘individual’s perception of their position in the life context of the culture and the value systems in which they live and in relation to their goals, expectations, standards and concerns’. None of the existing instruments address cultural and ethnic differences in various populations. There is only a single qualitative study from four European countries in the literature which revealed that a considerable number of concepts important to patients with HOA were not addressed with commonly used instruments. How HOA may affect patients in Asia is not studied. For instance, in the Oriental life, chopsticks use was reported to be associated with an increased prevalence of OA in the interphalangeal joint of the thumb, which may impact on QoL. Moreover, the perceptions of joint pain and physical disability may vary in different ethnic groups in relation to coping strategies and control beliefs. The degree of impact on psychological well-being may be affected by different social roles played by different ethnic groups. For example, in a previous study of our group, knee OA has a larger effect on ethnic Malays than the other ethnicities due to their need for kneeling to pray. Therefore, the aims of this study were to identify domains of QoL important to HOA patients in Singapore, representing an Asian socio-cultural context; and to assess existing QoL instruments in terms of coverage of patients’ concerns and applicability. The identified QoL domains would also help clinicians and researchers to develop instruments to measure treatment responses in clinical trials for HOA.

METHODS

We used focus group discussions as a method of data collection. This form of group interview allowed the participants to express their own thinking and feelings, and at the same time, interact and respond to other participants, which is essential to obtain information on patient perspectives.

Participants

We invited HOA patients who had received treatment in the rheumatology outpatient clinic at Singapore General Hospital. We included patients into the study who: (i) had a diagnosis of symptomatic HOA made by a rheumatologist according to the American College of Rheumatology (ACR) Classification Criteria; (ii) were adults aged 21 and above; (iii) were able to read and understand either English or Mandarin; and (iv) were able to speak coherently and provide written informed consent. We considered the number and composition of focus groups in terms of genders, ethnicities and languages, as homogeneous groups were more comfortable for patients to share their feelings and experiences. As HOA affects women more, fewer groups of men with smaller group size were considered. Singapore is a country with the majority being Chinese (74.1%), followed by Malay and Indian (22.6%), and others. English is the common spoken language (32.6%, 17% and 41.6% of Chinese, Malays and Indians speak English at home, respectively) while Mandarin is often used among elderly Chinese. We therefore considered focus groups among Chinese women (in either English or Mandarin); and to include at least one Chinese male group (in either English or Mandarin) and at least one minor ethnic group (in English) until saturation of topics had occurred.

Procedures

The ideal focus group composition was 4–12 participants, that allowed adequate interaction between focus group members and at the same time generate in-depth and more diverse information than other methods, such as surveys or individual interviews. We aimed to recruit 4–6 participants for each focus group session. We limited the maximum group size to six patients in order to allow each patient ample opportunities to share their ideas while allowing a diversity of opinions. However, we allowed the minimum number of two patients for groups that may have difficulty in recruitment (men and minor ethnic groups). We aimed to minimize the input from the moderator, to encourage more patient-related content. We followed the focus group procedure recommended by Krueger. Based on the phenomenological approach to study the experience of patients, the interview was designed to be open-ended. It proceeded from the most general to specific questions, minimizing the influence of moderator probes. In each focus group, the moderator asked open-ended questions on how HOA affected their lives and emphasized that the topic of the discussion was the impact of HOA per se. Each focus group discussion lasted approximately 2 hours, led by an experienced moderator and facilitated by a note-taker. The first 60 minutes focused on HOA-related impacts on QoL, and the first question for discussion was: ’In general, how
has having HOA affected your lives.’ Subsequent questions focused the discussion (30 minutes each) on the three broad domains of physical, mental and social well-being according to the WHO definition of health as a state of physical, mental and social well-being. All focus group discussions were audio-taped and transcribed verbatim, with subsequent translation into English. At the end of qualitative focus groups, patients filled a standardized questionnaire on socio-demographic, existing OA specific or generic instruments for HOA in either English or Chinese according to the spoken language used in the focus groups. The existing instruments for comparison were Functional Index for Hand Osteoarthritis (FIHOA), Modified – Score for Assessment and quantification of Chronic Rheumatic Affections of the Hand (M-SACRAH) and Health Assessment Questionnaire – Disability index (HAQ-DI). Patients were asked to rate on the relevance and importance of selected areas of life after the focus group discussions. All study procedures were performed in accordance with the ethics standards of the responsible committee on human experimentation and with the Helsinki Declaration of 1975, as revised in 1983. The study protocol was read and approved by the Centralized Institutional Review Board of SingHealth. All patients signed an informed consent prior to participation.

**Data analysis**

Focus group and interview discussions were voice recorded, transcribed verbatim and analyzed using thematic analysis. The open-ended discussion guide and data-driven analytic methods adopted in this study were based on elements of the grounded theory to encourage development of conceptual frameworks that were derived from participant input, rather than existing concepts. We analyzed the data through the process of open coding, axial coding and selective coding. First, two experienced coders independently coded the transcripts to generate initial codes that lead to greater understanding of categories – a process known as open coding. Next, the coders found the relationship of initial codes and combined them into categories and subcategories through the process of axial coding. The codes generated a coding schema comprising five fields (code title, definition, examples, guidelines for use and relationship to other codes). Through an unspecified number of rounds of consensus meetings, as facilitated by an independent psychologist trained in qualitative research (LW) the two independent coders then created a code book, which was then used as analysts code subsets of transcripts. The iterative process of independent coding and consensus meetings by the two independent coders and the psychologist continued throughout the whole data analysis process until both coders were satisfied that the codes could be consistently applied. The codes were then independently applied to all of the transcripts, and coding discrepancies were resolved at a final consensus meeting. Team analysis reduced bias associated with individual interpretation and increased study rigor. The final output of thematic analysis was a list of themes descriptive of QoL domains and their constituent subthemes, which elaborated on the scope of the domains as discussed by patients.

**Mapping of themes and subthemes to OA-specific instruments**

We compared the themes and subthemes identified from our focus group with items from three HOA-specific and one commonly used generic instruments for hand function. The existing instruments included for comparison were FIHOA, M-SACRAH, Australian/Canadian Hand Osteoarthritis Index (AUSCAN) and HAQ-DI. Content gaps were identified when subthemes and domains elicited from focus groups were not addressed by any item from these existing sources.

**RESULTS**

**Subjects**

Twenty-six patients with symptomatic HOA according to the ACR Classification Criteria participated in seven focus groups. Two and five focus groups were conducted in Mandarin and English, respectively. Table 1 shows the number and composition of focus groups in terms of gender, ethnicities and languages. Table 2 presents the characteristics of the participants.

**Domains obtained from focus groups**

Table 3 shows the domain and subthemes generated from qualitative data concerning QoL of HOA.

| Table 1 Number and composition of focus groups as stratified by gender, ethnicity and language |
|----------------|-----------------|--------|--------|---------|---------|
| Gender | Ethnicity | Language | No. of groups | No. of participants |
| Female | Chinese | Mandarin | 2 | 9 |
| Chinese | English | 3 | 12 |
| Malay | English | 1 | 2 |
| Male | Chinese | English | 1 | 3 |
patients and some examples of quotations for areas not covered or under-represented by the existing instruments. Broadly, the participants described the symptoms of HOA and how HOA affected their physical activities, psychological well-being and social aspects of life.

**Symptoms**

Patients often complained of symptoms of pain, stiffness and swelling. Pain was the most common symptom, mentioned in 24 out of 26 patients. Detailed descriptions of pain of different types, intensity and in relation to movement, were revealed. The participants generally did not perceive the symptoms as constant. They acknowledged the variability or fluctuation of one or more of those symptoms within a single day or over the week. Quite a few patients described morning pain and stiffness that changed in severity during a single day and infrequent swelling throughout the week. Many patients reported worsening of pain with weather, particularly on cold and rainy days. Several mentioned worsening symptoms in association with certain foods, such as bean products, seafood, salty biscuits and food with ‘cool’ properties in the Chinese culture.27

**Limitations in physical activities**

The participants described how their ability to perform daily activities was affected by the HOA. Loss of grip and pinch strength was often mentioned, and they described loss of agility, clumsiness of the hands and they kept dropping things. Hand disability affected the performance of small tasks in day-to-day living of the participants. They frequently spoke of difficulty in ‘opening jars/bottle drinks’, ‘tearing off food package’ or ‘using scissors’. They had difficulties in dressing, such as ‘zipping’, ‘buttoning’, ‘tying shoe laces’ and ‘fastening bra.’ HOA greatly interfered with their ability to do housework, including shopping for groceries, preparing meals, doing laundry and cleaning the house. For instance, a 55-year-old woman described difficulties in the Chinese style of quick frying in a wok, which is needed in cooking authentic Chinese food. Eating with cutlery was reported as another challenge. Several participants referred to numbness, pain and difficulties in eating with chopsticks: they had to put the chopsticks down and rest in between their meals. Participants who used to eat with hands also complained of hand pain and difficulties in pinching and holding the food to put to the mouth.

Hand osteoarthritis also affected rituals and religious practice. Participants spoke of the difficulty in prayer practice as their hands were painful and not strong enough to push themselves up from the floor from the kneeling position in prayers. Hand disability not only affected participants’ daily physical activities, but also restricted their participation in leisure activities, such as using the keyboard and mouse for internet surfing, flower arranging, baking and sewing. Many participants described the need to change their ways of doing things or their work flow. A few women described drip-drying clothes or towels instead of wringing them. A few mentioned buying new types of clothing or devices for daily lives.

| Variables                        | Mean age, years (range) | Gender            | Ethnicity         | Spoken language | Education | Occupation         | General health perception | HOA function                      |
|----------------------------------|-------------------------|-------------------|-------------------|-----------------|------------|---------------------|---------------------------|-----------------------------------|
| Demographics                     | 62.9 (52–78)            | Male 11.5%        | Chinese 88.5%     | Mandarin 34.6%  | Primary 19.2% | Employer/self employed 11.5% | Excellent/good 57.6%        | FIHOA (0–30) 3.5 (1–11) |
| Gender                           |                         | Female 88.5%      | Malay 11.5%       | English 65.4%   | Secondary 61.5% | Employee 26.9%         | Fair/poor 42.3%             | M-SACRAH function (0–100) 11.9 (0.25–41.6) |
| Ethnicity                        |                         |                   |                   |                 | Tertiary 19.2% | Looking for job 3.8%    |                           | M-SACRAH stiffness (0–100) 29.8 (1.5–74.5) |
| Spoken language                  |                         |                   |                   |                 |            | Housewife 23.1%        |                           | M-SACRAH pain (0–100) 22.8 (0–58) |
| Education                        |                         |                   |                   |                 |            | Retired 34.6%          |                           | HAQ (0–3) 0.56 (0–1.88)    |

FIHOA, Functional Index for Hand Osteoarthritis (FIHOA); HAQ, Health Assessment Questionnaire; HOA, hand osteoarthritis; M-SACRAH, Modified – Score for Assessment and quantification of Chronic Rheumatic Affections of the Hand.
| Domains under broad categories | Subthemes | Sample quotations from focus group discussions | Coverage by existing instruments |
|-------------------------------|-----------|-----------------------------------------------|----------------------------------|
| **A. Symptoms**               |           |                                               | FHOA  | M-SACRAH | AUSCAN | HAQ-DI |
| Pain                          | Specific description of pain | ‘digging into my bone’ [AU/F/67/Chi, FG1]; ‘being pricked by needles’ [ML/F/71/Chi, FG3]; ‘stabbing pain’ [T/M/52/Chi, FG5]; ‘sharp’ [F/M/62/Chi, FG3]; ‘throbbing’ [FM/62/Chi, FG3] | x x x |
|                               | Description of intensity of pain | ‘numbness’ [P3/F/71/Chi, FG4]; ‘tingling’ [RO/F/72/Chi, FG1]; ‘quite severe’ [RO/F/72/Chi, FG1]; ‘very intense’ [MM/F/65/Chi, FG3] | |
|                               | Pain affecting hand movement | ‘It is best to do nothing, then there will be no problem.’ [Kit/F/55/Chi, FG7]; ‘If you use your finger or thumb to apply pressure when you do certain things, then the pain usually increases.’ [J/M/62/Chi, FG5] | x x x |
| Stiffness                     | Pain affecting hand strength and work | Treating the condition is frustrating, and ‘it was a pain’ [J/M/62/Chi, FG5] | x x x |
|                               | Stiffness affecting finger/hand movement | Pain affecting hand movement | x x x |
| Swelling                      | Description of swelling, big, fat, red, warmth | ‘very red, very swollen’ [MA/F/78/Chi, FG1] | x x x |
|                               | Bones become big, boggy. Hard lump around the fingers | ‘The centre bone here is bulge out, you see, swollen.’ [ST/F/55/Chi, FG7] | |
|                               | Worsens with time of the day, morning, weather, environment, cold water, food/diet | ‘my fingers in the morning are very stiff’ [RO/F/72/Chi, FG1] | x x |
|                               | Variation or fluctuation of symptoms with time/environment/motion/mood | ‘The humidity is high, this part of my hand is very swollen.’ [MA/F/78/Chi, FG1]; ‘During rainy days, the joints will be painful.’ [G/F/6/Chi, FG4] | |
|                               | | ‘It tends to be quite accurate to predict the weather with your pain’ [AU/F/67/Chi, FG1]; ‘I try my best not to touch water, the hands like cannot close, cannot bend.’ [I/F/56/Chi, FG4]; ‘Cooling things may cause a flare up, ginseng tea, even green bean soup,’ [T/M/52/Chi, FG5] | |
|                               | Worsens with motion/movement | ‘It can come especially if you grip something or rinse.’ [PC/M/78/Chi, FG5] | |
|                               | Worsens with mood | ‘Sometimes when I am upset, I do get more pain.’ [MA/F/78/Chi, FG1] | |
| Domains under broad categories | Subthemes | Sample quotations from focus group discussions | Coverage by existing instruments |
|--------------------------------|-----------|------------------------------------------------|----------------------------------|
| B. Limitations in activities  | I have problems writing | 'Sometimes, I was so afraid that halfway, you know, I may give way the steering wheel.' [RO/F/72/Chi,FG1] | x x x x |
| B1 Daily activities           | I have difficulties in carrying | x x | x x x |
|                               | I have problems driving | | |
|                               | I cannot grip, pinch, hold things continuously | | |
|                               | I cannot open jars, bottled drinks | | |
|                               | I have difficulties in opening packaging | Three-in-one coffee [is] difficult to tear off.' [P1/F/59/Chi,FG2] | x x x x |
|                               | I cannot wring towels or clothes properly | 'I cannot fully wring dry a towel, I squeeze only 75%.' [P1/F/59/Chi,FG2] | x |
|                               | Hand is clumsy, loss of agility, I drop things | 'I have actually broken cups' [ST/F/59/Chi,FG7] | |
|                               | I have difficulties in doing housework, including shopping for groceries, preparing meals, doing laundry and cleaning the house | 'I find [it] difficult, when my hands swell, to turn your food as you fry. We Chinese like the wok frying and you really have to turn a lot so that's the difficulty.' [AU/F/67/Chi, FG1] | x |
|                               | I have problems in using tools, small gadgets. | 'Doing the housework is much slower than before.' [P3/F/71/Chi, FG2] | |
|                               | I have to slow down when doing things | 'I have occasion to wear my bracelet, I couldn’t do it.' [MA/F/78/Chi, FG1] | x |
|                               | I cannot wear my jewellery | 'Because of the swelling I cannot remove my rings. Even with soap.' [AU/F/67/Chi, FG1] | |
|                               | I have difficulties in self-care, including brushing teeth, cleansing after toileting, wiping body dry after bathing | 'I can’t wear rings. Because all the knuckles are all very big' [P3/F/71/Chi, FG2] | |
|                               | | 'It’s difficult to wear the ring, the ones with a pearl or whatever. It will turn to the inside; this makes me angry.' [MM/F/65/Chi, FG3] | |
|                               | | 'The jeans, cannot zip up and button after toilet' [IF/M/62/Chi, FG3] | x |
|                               | | 'When I am brushing my teeth, it really pulls. It is very thick tension.' [PC/M/78/Chi, FG3] | |
| Domains under broad categories | Subthemes | Sample quotations from focus group discussions | Coverage by existing instruments |
|--------------------------------|-----------|------------------------------------------------|---------------------------------|
| **Problem with dressing, including buttoning (clothes), pulling up (pants), zipping up (pants), fastening or tying shoelace.** | 'Sometimes I don’t even button, I tie up with a belt.' [T/M/52/Chi, FG5] 'Buttoning your shirt can be a real problem.' [J/M/62/Chi, FG5] 'All the small actions, like buttoning yourself, zipping, you know, all these require your thumb. You cannot do with the other fingers.' [J/M/62/Chi, FG5] | | **FHOA** | **M-SACRAH** | **AUSCAN** | **HAQ-DI** |
| | | | | **x** | **x** | **x** | **x** |
| **I have difficulties in using cutlery** | 'Half way eating, I have to put the chopsticks on the table rest my hand.' [P1/F/59/Chi, FG2] 'Still can eat with the hands, but here pain here pain.' [N/F/58/Mal, FG6] | | | | | |
| **I have problems using electronic devices** | 'Have difficulties in doing some typing, entering data.' [S/F/59/Chi, FG7] | | | | | |
| **It affects my religion/ritual practices** | 'Muslim prayers have to do movements; I cannot push myself up from the floor.' [K/F/73/Mal, FG6] | | | | | |
| **I need to change the ways of doing things, change of work flow, etc.** | 'I couldn’t fasten the bra, so I buy bra that’s fasten in front.' [P3/F/71/Chi, FG3] 'For cleansing window, I will open the windows when it rains and let it wet.' [Sh/F/60/Chi, FG3] 'I change to the electrical tooth brush, and then you hold this way. Helps a lot.' [T/M/52/Chi, FG5] 'Squeezing also cannot, so I have to hang it dry, all these things.' [K/F/73/Mal, FG6] 'I like cooking, only eat light but not so heavy things, you have to distribute your work.' [Sh/F/60/Chi, FG3] | | | | | |
| Domains under broad categories | Subthemes | Sample quotations from focus group discussions | Coverage by existing instruments |
|-------------------------------|-----------|-----------------------------------------------|---------------------------------|
| B2. Leisure activities        | I cannot do things I enjoyed doing | 'I like to surf the net and so it’s quite miserable.' \[Au/F//Chi, FG1\]  
   |                       | 'In doing flower arrangement, I cannot get what I want, I always break the plant.' \[P3/F/71/Chi, FG2\]  
   |                       | 'I like to cook. Basically I stop doing [it] because opening jars is difficult and washing pots and pans become quite heavy. I try not to stress the joints' \[T/M/52/Chi, FG3\]  
   |                       | 'I love sewing, patchwork, embroidery work. It affected very lot. Even handicraft work [I] also cannot do.' \[FL/F/69/Chi, FG7\]  |
|                               |           |                                               | FHOA  M-SACRAH  AUSCAN  HAQ-DI   |
| C. Impact on psychological well-being |                  | 'Sometimes I cannot even open the cap. I have to ask others for help. Feel very frustrated.' \[N/F/62/Ch, FG4\]  
|                               |           | 'You can’t even hold a needle now that’s very frustrating.' \[MA/F/78/Chi, FG1\]  
|                               |           | 'I also cannot fasten my bra. It is very frustrating' \[MA/F/78/Chi, FG1\]  |
|                               | I become irritable, impatient, and I loose temper easily | 'I get very annoyed and on reflection I feel very bad.' \[FL/F/69/Chi, FG7\]  
|                               |           | 'All these minor, minor problems irritate me.' \[FL/F/69/Chi, FG7\]  |
|                               | I feel sad, downhearted, depressed | 'In the first few years, I really want to jump down the building, it was very miserable.' \[FL/F/58/Ch, FG3\]  
|                               |           | 'Ah pain and I cannot do everything I do, everyday all I cannot do, one day I really feel to go down from the window' \[N/F/58/Mal, FG2\]  |
|                               | I feel helpless, loss of control | 'I have to take care of him, my hands are also painful. I have to take care of another patient, I am a patient myself' \[FL/F/58/Chi, FG3\]  |
|                               | I feel guilty | 'It] makes me feel very guilty because I get angry with him for not able to help me' \[MA/F/78/Chi, FG1\]  |
Table 3 (continued)

| Domains under broad categories | Subthemes | Sample quotations from focus group discussions | Coverage by existing instruments |
|-------------------------------|-----------|----------------------------------------------|--------------------------------|
| I feel not being understood, other people do not understand what I am suffering | 'Just suffer in loneliness or suffer in silence' [RI/F/71/Chi, FG1] | FIHOA M-SACRAH AUSCAN HAQ-DI |
| I feel embarrassed | 'They don’t understand our problem you know. They do not see the severity.' [PS/F/71/Chi, FG2] | |
| I am concerned about the look of the fingers and the aesthetic changes; it affects my self-confidence and self-esteem; I feel older than my age, it reminds me of ageing | 'They will think that you are trying to catch their attention.' [PS/F/57/Chi, FG2] | |
| | 'Because it will not bleed, it's also not some serious illness, it’s no meaning if you keep talking about it (the pain).' [MM/F/65/Chi, FG3] | |
| | 'It’s like this pain, own-self pain' [MM/F/65/Chi, FG3] | |
| | 'Even the doctors themselves felt that hand OA is not a problem' [MM/F/65/Chi, FG3] | |
| I worry (about the current condition, worry that it gets worse) | 'Very embarrassing that you drop things' [RO/F/72/Chi, FG1] | |
| | 'In the supermarket, cannot take the plastic bag, open it, it’s quite embarrassing' [PS/F/57/Chi, FG2] | |
| | 'It is embarrassing. In front of your friends, when you eat, they are looking at your ugly fingers.' [PS/F/71/Chi, FG2] | |
| | 'They are getting crooked, in the future maybe it will look very ugly we can’t help it.' [AU/F/67/Chi, FG1] | |
| | 'In that sense that why the mind is younger but the body is not.' [AU/F/67/Chi, FG1] | |
| | 'Sometimes when I want to dress up for occasion, your clothes look quite nice and new, but your fingers are quite old that kind of feeling' [MM/F/78/Chi, FG3] | |
| | 'But if you look at my hands, my hands shows my age you know' [PS/F/71/Chi, FG2] | |
| | 'They are very ugly, not even pretty when wearing rings' [AU/F/62/Chi, FG4] | |
| | 'I’m just worried that eventually all my other eight fingers will also become crooked.' [PS/F/62/Chi, FG2] | |
| | 'I’m worried that my thumb will be totally deformed that I cannot use.' [PS/F/62/Chi, FG2] | |
| Domains under broad categories | Subthemes | Sample quotations from focus group discussions | Coverage by existing instruments |
|-------------------------------|-----------|-----------------------------------------------|----------------------------------|
| I worry about losing independence | I am unable to take part in social activities I want to | 'Then I know I will eventually need one [maid] but that frightens me' [MA/F/78/Chi,FG1] 'When I am older, do I need my children to help me, do I need people to bathe me? That is a suffering for me.' [A/F/62/Chi,FG4] 'I am afraid if I carry her [granddaughter], I might drop her.' [MA/F/78/Chi,FG1] 'I have to force myself to fold in my thumb to carry my grandchildren up' [FL/F/69/Chi,FG7] 'It’s difficult for me to help them retrieve their toys and the child doesn’t understand you. He wants grandma to do it and not someone else.' [Au/F/67/Chi,FG1] 'My wife automatically hands [over] heavy things to me to carry, and I have to carry.' [PC/M/78/Chi,FG5] 'Because I didn’t cook their [grandchildren] favourite curry. I cannot stand long then my hands also cannot wash. So they didn’t come, never come.' [K/M/75/Chi,FG7] 'Last time got so many friends; 1 week three times we go to mosque. Now like no heart to go, no heart to make friends.' [N/F/58/Chi,FG6] 'I used to enjoy shopping with friends, now I cannot walk, my hands cannot carry things. I don’t want to trouble people, so I try not to go.' [N/F/58/Chi,FG6] 'I used to have a lot of friends, now I don’t attend those activities, will more or less lose contact, like lose some friends.' [A/F/62/Chi,FG4] 'When the pain [is] coming, I don’t let people talk to me. I want to stay myself only.' [N/F/58/Mal,FG6] | FIHOA  M-SACRAH  AUSCAN  HAQ-DI |
Impact on psychological wellbeing

Hand osteoarthritis symptoms had prominent effects on the patients' psychological responses. Quite a few patients reported frustration coming from difficulties in doing small tasks. They also reported being irritated or angry when in pain. In many circumstances, what affected the psychological status of participants was not just the disease itself, but also coming from the feeling of not being understood. They reported that others' perceptions of their illness were not serious and were considered minor. There were two patients who described suicidal ideation and attempts at some point in their lives, either directly or indirectly as a result of the symptoms and disabilities incurred by HOA.

Aesthetic concern was a salient factor related to their psychological status, especially for female participants. They expressed concern and embarrassment about their deformed hands. One woman described embarrassment while eating together with her friends. Worrying about the prognosis was frequently voiced; many participants raised worries about the progression of deformities to other fingers.

Impact on social life

The physical, psychological and social effects of HOA were interrelated. A 58-year-old woman stated that she used to go out with friends, but then 'have no heart to go' and 'just want to sit at home'. Participation in various family roles is affected, including taking care of aging spouses and young grandchildren. One participant expressed how his inability to act as a grandmother who cooks the grandchildren's favorite food and that had affected family gatherings.

Our qualitative study revealed that HOA affected work productivity. Six participants (23%) mentioned that as a result of their HOA, they were absent from work, took no-pay leave, needed to change their work duties and even quit their job or could not participate in profitable activities. A patient who was unable to organize heavy and frozen items in a supermarket said: ‘Last time sold people baju [traditional clothing], make money you know a lot of money. Now cannot.’ [KF/73/Mal, FG6]

‘To me, the impact is very big, at least I cannot work,’ [SH/60/Chi, FG3]

‘Work productivity is affected. Usually, they will want you to be fast, then how to be fast? Cannot!’ [LQ/F/55/Chi, FG7]

‘It’s so swollen and big and painful that you cannot even work, you cannot use that finger as a reason to take medical leave. Then I ask my subordinates to work on the heavier duties.’ [SF/F/60/Chi, FG3]

Impact on quality of life

The patients revealed various ways of managing HOA symptoms and the impacts on their life. They sought...
medical treatment from Western trained doctors, alternative treatments, searching for information about HOA, exercising and stretching hands to relieve the discomfort. They changed their ways of performing daily activities, such as using assistive devices and rearranging ways of completing tasks. Some reported reliance on religious support and support from family and friends. Other coping strategies included bearing the symptoms, positive thinking, accepting the condition and adjusting expectations. Patients revealed many concerns in conditions other than HOA that impact their QoL. Pain and symptoms from OA from other body sites, particularly knee pain and back pain, were commonly brought up. Other co-existing conditions affecting their hands, like carpal tunnel syndrome and trigger finger, were frequently mentioned. For most patients, they could not distinguish whether hand symptoms were related to HOA or something else. Despite not being the focus of discussion, participants revealed many unmet health care needs and dissatisfaction in standard health care. The lack of cure and lack of ways to reverse or even to slow down the deforming process were frequently mentioned. They lamented that standard care was unable to relieve their pain and symptoms, and was incapable in helping them to cope with disabilities, and so they sought alternative treatments, including acupuncture, massaging and over-the-counter supplements. One male participant commented on occupational therapy service as: ‘If you give me useless or impractical advice what is the purpose? They charge high you know. In fact the charges are higher than the doctors.’ Other unmet needs included high cost of supplements, high charges for allied health services, high cost of assistive devices and high charges for alternative therapies like acupuncture.

**Concepts covered in existing instruments**

Fifteen of all the 43 subthemes (34.9%) were contained in at least one existing HOA instrument (Table 3). The existing instruments covered pain and stiffness, but lacked the detailed description of pain, its intensity and relation to environment. The symptoms of swelling were not included in existing instruments. While AUSCAN had items on stiffness in the morning, only M-SACRAH incorporated symptom fluctuations within a single day; symptom fluctuations with other factors were not included in the existing instruments. Most of the categories regarding functional impacts were covered in the instruments; however, the need for changing ways of doing things/tasks was not covered. Problems using keyboards, mouse or other electronic devices, and the effect on religion practices, were emerging areas in the current study. Furthermore, none of the existing instruments covered impacts on psychological or social

**Table 4** Rating of areas of life that is relevant to patients with hand osteoarthritis (HOA)

| Area of life affected by HOA                                    | Relevance grading | Percentage of patients |
|----------------------------------------------------------------|-------------------|------------------------|
| Pain and other symptoms                                       | Not at all relevant | 3.8                    |
| (e.g., hand pain, stiffness, numbness and other discomfort in the hand) | Somewhat relevant | 38.5                   |
| (e.g., feeling sluggish, poor concentration, exhaustion)      | Highly relevant   | 57.7                   |
| Fatigue                                                       | Not at all relevant | 23.1                   |
| (e.g., walking, bathing, doing housework)                     | Somewhat relevant | 61.5                   |
| (e.g., depression, anxiety, resentment)                       | Highly relevant   | 15.4                   |
| Physical function                                             | Not at all relevant | 15.4                   |
| (e.g., going out with family, friends or colleagues, work performance, commitment to social activities) | Somewhat relevant | 46.2                   |
| Emotional health/mood                                         | Not at all relevant | 11.5                   |
| (e.g., low self-esteem, feeling not attractive, embarrassment) | Somewhat relevant | 57.7                   |
| Burden to others                                              | Not at all relevant | 30.8                   |
| (e.g., feelings of worry, stress, burden to others)           | Somewhat relevant | 46.2                   |
| (e.g., feeling not attractive, embarrassment)                 | Highly relevant   | 15.4                   |
| Self-image                                                    | Not at all relevant | 38.5                   |
| (e.g., going out with family, friends or colleagues, work performance, commitment to social activities) | Somewhat relevant | 46.2                   |
| Social & occupational activities                               | Not at all relevant | 46.2                   |
| (e.g., going out with family, friends or colleagues, work performance, commitment to social activities) | Somewhat relevant | 34.6                   |
| (e.g., going out with family, friends or colleagues, work performance, commitment to social activities) | Highly relevant   | 19.2                   |
aspects of life, participation in family roles, work productivity and aesthetic concerns.

Rating of relevance of pre-selected domains
Of the seven areas of life identified from existing scales and the literature, ‘pain and other symptoms’ were rated as ‘highly relevant’ by the largest proportion (58%) of patients (Table 4). ‘Emotion health/mood’ (30%) and ‘physical function’ (23%) were next most frequently rated as ‘highly relevant.’ Although not rated high by most, nearly one-quarter of participants rated self-image and social life as ‘highly relevant.’

DISCUSSION
This study demonstrated that HOA affected various domains of life of patients. Pain and hand disability are major problems in HOA patients, which are consistent with previous studies. Our qualitative study revealed detailed description of pain and intensity and variability with time, movement and environment. In addition to limitations to physical activities, we identified the need to change ways of doing things and the inability to perform or enjoy leisure activities as new domains. We also identified the domain of psychological impact and limitations on social roles as important domains that are not covered by existing instruments. The results also highlight the aesthetic concern among HOA patients, particularly among women.

A recent qualitative study among subjects with HOA from European counties, which is also the single qualitative study in HOA, noted similarly that many important domains were not well covered by existing instruments. Other similar findings from our study as compared to the European study included different qualities of pain, aesthetic concerns, reduced leisure activities, need to change habits, and psychological impacts. Our study further revealed hand dysfunction in the Asian perspective, such as difficulties in cooking, eating with cutlery, ritual and prayer practice. The impact on family role participation is a specific area in Asian lifestyles, including difficulties in cooking, eating with cutlery, ritual and prayer practice. The impact on family role participation is highlighted. The domains and subthemes we

difficulties in performing simple tasks in life. They felt not being understood as people perceive HOA as not a serious problem. They also had low moods as a result. Two participants even reported having suicidal thoughts at some point in their lives, directly or indirectly related to pain and hand dysfunction. Psychological impact as an important domain that has been neglected for patients who suffer from HOA should be explored and included in future instruments developed to measure QoL for HOA. Another remarkable finding in our study was the impact on work productivity. Although less than half of our participants were at work at the time of interview, a quarter reported reduction in work productivity. As people work to an older age in an ageing society, the impact on work productivity would be an interesting topic to explore in order to lengthen individuals’ productive ages, as well as preserving the labor force in society. Working with a computer or electronic devices may be an important activity in the modern society and also in the workplace, which suggests the adaptation of devices for the ageing population, to keep abreast with the times would be necessary. Although not the focus of this study, numerous unmet medical needs for patients with HOA were revealed.

There are a few limitations to our study. First, we have a relatively small sample size for men and minor ethnicities. The low percentage of men in our participants is compatible with the significant lower prevalence of HOA in men compared to women. Another limitation is that we could not recruit Indian participants despite a prolonged recruitment period. Although Indians represent a smaller composition in the population in Singapore, it will be interesting to include their perspectives. Finally, the domains for the rating of relevance were pre-selected from a literature review, and were not derived from patient data or prespectives. Ideally, the domains for rating should emerge from the qualitative findings and they should be rated in a larger sample.

CONCLUSION
Numerous domains important to patients with HOA are not well covered by existing instruments. Levels of pain, psychological impacts, impacts on social roles and aesthetic concerns are domain gaps identified in our qualitative study reflecting the Asian perspective. Several areas are specific to Asian lifestyles, including difficulties in cooking, eating with cutlery, ritual and prayer practice. The impact on family role participation is highlighted. The domains and subthemes we
identified will be important for the development of instruments to measure QoL outcomes in clinical trials for HOA.

ACKNOWLEDGEMENTS

We thank Prof. Cheung Yin Bun for valuable advice on design of the study and acquisition of funding. We thank Dr Mandy Ow for contribution to training of modulators and open coding for this qualitative study. We are indebted to all participants who gave valuable information to this study.

AUTHOR CONTRIBUTION

YYL conceived the study, contributed to study design, acquisition of data, data analysis and interpretation and drafted the manuscript. LW assisted in acquisition of data, performed data analysis and interpretation and drafting of manuscript. JT participated in study design and drafting of manuscript. All authors read and approved the final version of the manuscript.

CONFLICT OF INTEREST STATEMENT

All authors declare no conflict of interest.

FUNDING STATEMENT

This study was supported by the SingHealth Foundation Grant (SHF/FG549S/2011).

REFERENCES

1 van Saase JL, van Romunde LK, Cats A, Vandenbroucke JP, Valkenburg HA (1989) Epidemiology of osteoarthritis: Zoetermeer survey. Comparison of radiological osteoarthritis in a Dutch population with that in 10 other populations. Ann Rheum Dis 48, 271–80.
2 Lawrence RC, Felson DT, Helmick CG et al. (2008) Estimates of the prevalence of arthritis and other rheumatic conditions in the United States. Part II. Arthritis Rheum 58, 26–35.
3 Dillon CF, Hirsch R, Rasch EK, Gu Q (2007) Symptomatic hand osteoarthritis in the United States: prevalence and functional impairment estimates from the third U.S. National Health and Nutrition Examination Survey, 1991–1994. Am J Phys Med Rehabil 86, 12–21.
4 Slatkowsky-Christensen B, Mowinckel P, Loge JH, Kvien TK (2007) Health-related quality of life in women with symptomatic hand osteoarthritis: a comparison with rheumatoid arthritis patients, healthy controls, and normative data. Arthritis Rheum 57, 1404–9.
5 Michon M, Maheu E, Berenbaum F (2011) Assessing health-related quality of life in hand osteoarthritis: a literature review. Ann Rheum Dis 70, 921–8.
6 WHO (1998) The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. Soc Sci Med 46, 1569–85.
7 Stamm T, van der Giesen F, Thorstensson C et al. (2009) Patient perspective of hand osteoarthritis in relation to concepts covered by instruments measuring functioning: a qualitative European multicentre study. Ann Rheum Dis 68, 1453–60.
8 Hunter DJ, Zhang Y, Nevitt MC et al. (2004) Chopstick arthropathy: the Beijing Osteoarthritis Study. Arthritis Rheum 50, 1495–500.
9 Thumboo J, Chew LH, Lewin-Koh SC (2002) Socioeconomic and psychosocial factors influence pain or physical function in Asian patients with knee or hip osteoarthritis. Ann Rheum Dis 61, 1017–20.
10 Ibrahim SA, Burant CJ, Mercer MB, Siminoff LA, Kwoh CK (2003) Older patients’ perceptions of quality of chronic knee or hip pain: differences by ethnicity and relationship to clinical variables. J Gerontol A Biol Sci Med Sci 58, M472–7.
11 Abraido-Lanzaf GM, Alarcón G, Appelrouth D et al. (1990) The American College of Rheumatology criteria for the classification and reporting of osteoarthritis of the hand. Arthritis Rheum 33, 1601–10.
12 Krueger RA, Casey MA (2000) Focus Groups – A Practical Guide for Applied Research, 3rd edn. Sage, Thousand Oaks, CA.
13 Srikanth VK, Fryer JL, Zhai G et al. (2005) A meta-analysis of sex differences prevalence, incidence and severity of osteoarthritis. Osteoarth Cartilage 13, 769–81.
14 Singapore Census of population (2010). (http://www.singstat.gov.sg/publications/publications-and-papers/cop2010/cop2010-administrative-report). Accessed 25 June, 2015.
15 Tang KC, Davis A (1995) Critical factors in the determination of focus group size. Fam Pract 12, 474–5.
16 Parsons M, Greenwood J (2000) A guide to the use of focus groups in health care research: Part 1. Contemp Nurse 9, 169–80.
17 Kitzinger J (1995) Qualitative research. Introducing focus groups. BMJ 311, 299–302.
20 Lasch KE, Marquis P, Vigneux M et al. (2010) PRO development: rigorous qualitative research as the crucial foundation. Qual Life Res 19, 1087–96.
21 WHO (1948) Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference June; signed on 22 July by the representatives of 61 States (Official Records of the World Health Organization, no. p. 100) and entered into force on 7 April 1948; 2, 19–22.
22 Dreiser RL, Maheu E, Guillou GB, Caspard H, Grouin JM (1995) Validation of an algofunctional index for osteoarthritis of the hand. Rev Rhum Engl Ed 62, 43S–53S.
23 Leeb BF, Sautner J, Andel I, Rintelen B (2003) SACRAH: a score for assessment and quantification of chronic rheumatic affections of the hands. Rheumatology (Oxford) 42, 1173–8.
24 Fries JF, Spitz P, Kraines RG, Holman HR (1980) Measurement of patient outcome in arthritis. Arthritis Rheum 23, 137–45.
25 Strauss A, Corbin J (1990) Basics of qualitative research: Grounded theory procedures and techniques. SAGE Publications, Newbury Park.
26 Bellamy N, Campbell J, Haraoui B et al. (2002) Dimensionality and clinical importance of pain and disability in hand osteoarthritis: Development of the Australian/Canadian (AUSCAN) Osteoarthritis Hand Index. Osteoarthritis Cartilage 10, 855–62.
27 Anderson EN (2013) Folk nutritional therapy in Modern China. In: Hinrichs TJ, Barnes LL (eds) Chinese Medicine and Healing, pp 259–60. Harvard University Press, Cambridge.
28 Mehta K (2006) Interdependence in Asian Families. Intergener Relatsh 4, 117–25.