# Quality of Life among Lower Limb Amputees with Chronic Phantom Limb Pain or Stump Pain at a Tertiary Institution's Pain Clinic

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**Background**: Phantom pain and stump pain in amputees have negative physical and psychological impacts. These effects may influence the quality of life (QoL) of lower limb amputees.

Objective: To explore QoL of lower limb amputees treated at Ramathibodi pain clinic.

**Materials and Methods**: All lower limb amputees treated at Ramathibodi pain clinic in 2020 were invited to answer questionnaires, including demographic data, the Short Form-36 Health Survey (SF-36), and the Hospital Anxiety and Depression Scale (HADS). Participants were recruited to join a focus group discussion and individual interviews. Qualitative data were collected, and then analyzed using content analysis and inductive thematic analysis.

**Results**: Twenty-two participants were recruited. Average SF-36 score was 49.17±10.07. Physical component summary was 23.36±15.27 and mental component summary was 68.02±16.45. HADS were 5.91±3.69 and 5.23±3.42 for anxiety and depression, respectively. Eight participants were selected for focus group discussion and individual interviews. Five themes emerged, including biopsychosocial effects of amputation, pain among amputees, concepts of encouragement in life, gaps between patients and multidisciplinary team staff, and effects of the COVID-19 pandemic.

**Conclusion**: Lower limb amputees had low QoL. Amputation was found to restrict patients' physical function, and good pain management was reported to be crucial to help amputees cope and accept their condition. Positive self-esteem and social support also played a significant role. Inadequate communication was found to be the main deficit requiring attention. Lockdown policies during the COVID-19 pandemic affected QoL but pain intensity was maintained with management via telemedicine.

Keywords: Lower limb amputee; Quality of life; Phantom limb pain; Stump pain

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Chronic phantom limb pain (PLP) and stump pain are the major medical problems in amputees. Chronic PLP usually presents as a painful or unpleasant sensation in the distribution of the lost or deafferentated body part. It usually develops within six months after amputation and can persist for years. The prevalence of PLP in long-standing amputees

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Pasutharnchat K, Juengsmarn A, Jarupongsa J. Quality of Life among Lower Limb Amputees with Chronic Phantom Limb Pain or Stump Pain at a Tertiary Institution's Pain Clinic. J Med Assoc Thai 2022;105:228-39. **DOI:** 10.35755/jmedassocthai.2022.03.13282 has been reported to be as high as  $85\%^{(1)}$ . The stump pain, which is localized in the remaining body part, occurs immediately after amputation. Having the prevalence of 55% to 74%, this troublesome pain can also become chronic<sup>(2)</sup>.

Pathophysiology of postamputation pain might be the results of neural dysregulation in different levels along the pain pathway. In the brain, the somatosensory cortical reorganization in the representing area of limb deafferentation is considered the main mechanism of PLP and phantom sensations. In spinal cord, neural reorganization is also found in the dorsal ganglia after deafferentation from a peripheral nerve injury. In peripheral nerve, inflammatory response and axonal sprouting increase the ectopic afferent input, which could be responsible for the stump pain, neuroma pain, and phantom phenomena<sup>(1)</sup>.

Regardless to the cause, amputation has brought considerable changes in all amputees' lives, especially in the lower limb amputees<sup>(3)</sup>. Physical, psychological, and emotional effects can degrade the quality of life  $(QoL)^{(4)}$ .

Previous studies have attempted to explore amputees' QoL, either in quantitative or qualitative methods<sup>(2-16)</sup>. The quantitative studies have investigated it through specially designed questionnaires<sup>(2,3,5-11)</sup>. Emotional comorbidities, such as anxiety and depression, were also evaluated<sup>(5,6)</sup>. However, indepth details of the amputees' live experiences were not explored by the quantitative methods. A previous quantitative study in Thais suffering from unilateral lower limb amputation, showed that they had primarily fair health related QoL<sup>(11)</sup>. Employment status, use of assistive devices or artificial limbs, medical comorbidities, PLP, and residual stump pain were found to be the predictive factors of QoL in lower limb amputees(3). Anxiety was more prevalent in younger amputees and depression was more common in the elderly group<sup>(5)</sup>. Additionally, impaired QoL and perceptive changes of body image had a significant impact on adherence to the rehabilitation program and the functional prognosis<sup>(5)</sup>.

Qualitative studies, on the other hand, have been developed to deeply explore the impacts of PLP and amputation on amputees' well-being. They also examined how their physical, psychological, and social aspects were affected<sup>(12-16)</sup>. These studies could provide more understanding on amputees' live experiences. In the previous qualitative studies, participants were recruited from the rehabilitation centers, or the amputee supporting groups and included either upper limb or lower limb amputees. QoL could be diverse among amputees with different circumstances, for examples, site of amputation, management that they have received, and psychosocial backgrounds. In the authors' institution, all amputees with severe PLP or stump pain are referred to pain management clinic, where the pain specialists have spent time to explore the patients' pain and its consequences. The author previously conducted a descriptive study and found that medication could control their pain effectively without significant serious adverse effects<sup>(17)</sup>. To the best of the authors' knowledge, in-depth study of QoL of the lower limb amputees treated in pain management clinic is still lacking. Thus, in the current study, the authors focused on this subpopulation.

#### Objective

The objective of the current study was to explore QoL of lower limb amputees with chronic PLP or stump pain treated at Ramathibodi pain clinic.

#### **Materials and Methods**

To determine the sample size for the present study, the authors reviewed Ramathibodi Hospital's electronic medical records. Data from all amputated patients attending the Ramathibodi pain clinic in 2020 who met the inclusion criteria were reviewed, constituting of 26 patients. A previous study on qualitative research methods suggested that the number of five to 50 participants is adequate for the interview studies, and that a range of factors are crucial, including the quality of data, the scope of the study, the nature of the topic, the amount of helpful information collected, the qualitative method, and study design used<sup>(18)</sup>. Consequently, the authors concluded that data saturation would be achieved by including all 26 patients.

After the present study was approved by the Ramathibodi Hospital Ethical Committee (approval number MURA2020/872), all lower limb amputated patients that attended the Ramathibodi pain clinic between January and December 2020 were invited to provide informed consent to participate in the present study. The inclusion criteria were 1) patients aged 18 to 80 years, 2) undergoing lower limb amputation such as hip disarticulation, above knee amputation (AKA) or below knee amputation (BKA), 3) being diagnosed with chronic PLP or stump pain, 4) being on pain management for more than three months, and 5) being able to fluently use and understand the Thai language. Patients who did not provide a consent, those with a prior disability, those with concomitant chronic pain, those with psychological disorders before amputation, and those with communication problems such as deafness, blindness, or cognitive impairment were excluded from the study.

#### Study design

A cross-sectional descriptive design was used for the present study.

#### **Data collection**

**Quantitative data**: Demographic data and clinical profiles were collected using a data collection form designed for the purposes of the current study. Interview topics were examined using interviewer-administered questionnaires. The quantitative data were also collected using two questionnaires, 1) the Thai version of Short Form-36 Health Survey (SF-36)<sup>(19)</sup> for evaluating individual health-related QoL, and 2) the Thai version of Hospital Anxiety and Depression Scale (HADS)<sup>(20)</sup> for determining the level of anxiety and depression.

- What are the sequences of your daily activities from the early morning to the nighttime?
- How does the pain (phantom limb pain and/or stump pain) affect you physically, mentally, and socially?
- Is there anything you feel that it can aggravate the pain?
- How do you cope and adjust your life according to the pain/ amputation?
- For non-medical management, what do you usually do to relieve or to cope with the pain?
- Do you have any person that support you? In which way, that they support?
- Please give us your feedback regarding to the medical teams and the treatment as well as the supports they have provided.
- How do you understand your disease and treatment? What is your expectation for the treatment?
- During COVID-19 pandemic, how have your life been? How much COVID-19 affect your life?

Figure 1. Examples of topic guide for the focus group discussion and interviews.

The SF-36 is a generic measure of QoL and consists of eight subscales (domains), which are physical functioning (PF), role physical (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role emotional (RE), and mental health (MH)<sup>(21)</sup>. The validity and reliability of SF-36 have been well established in different disease conditions and settings<sup>(22,23)</sup>. Scores for each variable were summed, then transformed into a Likert scale ranging from 0 (worst) to 100 (best).

The HADS is created to evaluate anxiety and depression in a general patients' medical population. The benefits of the HADS are its simplicity, quickness, and comfort of use. The HADS was reported to have adequate validity for assessing symptom severity for cases of anxiety disorders and depression in somatic, psychiatric, and primary care patients, and in the general population<sup>(24)</sup>. Scores equal to or greater than 11 out of a total score of 21, indicated anxiety or depression.

**Qualitative data**: To establish the semi-structured focus group discussion and individual interviews, participants who had undergone quantitative data collection were invited by convenience. Firstly, ten participants were included. If a participant was not available, the next participant was invited. The number of participants may increase, depending on the saturation of data. Field notes were made while the group discussion and interviews were being conducted at a quiet room in the pain clinic, taking 120 to 180 minutes. The group discussion and interviews were recorded and transcribed verbatim for data analyses.

Three female investigators, including a pain specialist (KP), a pain fellow (AJ), and an experienced pain nurse (JJ), altogether moderated the focus group discussion and individual interviews. As three investigators were pain clinic staff, some participants might have previously encountered and got acquainted with the investigators during the treatment.

After participants were informed of the objectives and interview processes. The focus group discussion was organized by proposing issues that were based on the literature and related to the study objectives. Semi-structured and open-ended questions were used to obtain more in-depth information, covering activity in daily life as amputees, factors affecting pain, how pain affecting participants' life, roles of supporting people, feedbacks on medical teams and treatment, comments on group discussion, and way of life during the COVID-19 pandemic. Examples of the topic guide for group discussion are shown in Figure 1.

After group discussion, participants were individually interviewed to handle sensitive issues and complete the data collection. Each participant was given a chance to talk about other issues related to pain and QoL that were not covered in the group discussion.

#### Data analysis

Demographic data were analyzed using PASW Statistics for Windows, version 18.0 (SPSS Inc., Chicago, IL, USA). Categorical data and continuous data were reported as frequency (%). SF-36 and HADS data were reported as mean and standard deviation (SD). Spearman's rank correlation was used to test for correlations between quantitative variables, including SF-36 and HADS scores. The criterion for statistical significance was set at p-value less than 0.05. The Mann-Whitney U test was used to compare SF-36 and HADS scores between pain intensity groups.

Qualitative data obtained from the interview were analyzed by categorizing general answers, which were then transcribed as descriptive text. The accuracy of the transcripts was verified. The data were analyzed concurrently with data collection to develop a focused research process. Content analysis and inductive thematic analysis techniques were used. Three investigators separately coded sentences or phrases. The coding was descriptive and designed to capture the content of the data. Several meetings were held to discuss the emerging codes until agreement was reached. The codes were labeled together in categories. The investigators decided which codes and categories answered the research objectives, and predominant themes were identified. New themes

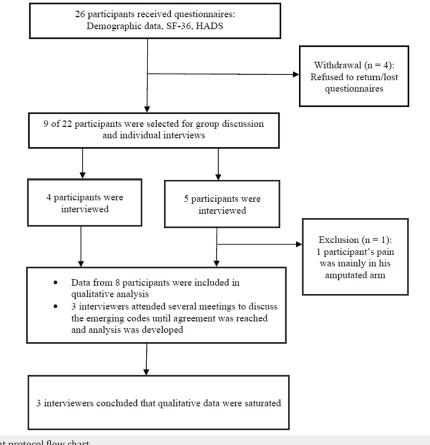


Figure 2. Patient protocol flow chart.

were also discussed. Together, the investigators explored various thematic maps until a consensus was established and theme labels were agreed. Additional individual interviews regarding the prominent themes from the group discussion were then performed to saturate the data for all themes.

#### Results

Flow chart of patient protocol is shown in Figure 2.

#### For quantitative data

Twenty-six participants were enrolled. Of these, 22 participants completed the questionnaires (84.16%). Demographic data are shown in Table 1. The majority were male (68.18%), and most participants were aged over 60 years (45.45%). Family members, such as spouse (40.19%) and parents/children (36.36%) were main caregivers. Prosthetic limbs were use in 63.64% of participants. Average pain score was 3/10 (IQR 1 to 5). The most common cause of amputation was peripheral vascular disease (50%). Gabapentinoids were the most essential analgesic, used in 95.45% of participants, following by tramadol (54.55%).

#### For quantitative data

The SF-36 scores for each of SF-36 domains are shown in Table 2. Average SF-36 score was  $47.19\pm10.07$ . Participants were found to have lower physical component summary (PCS) score of  $26.36\pm15.27$ , compared to mental component summary (MCS) score of  $68.02\pm16.45$ . The mean HADS scores were  $5.91\pm3.69$  for anxiety, and  $5.23\pm3.42$  for depression, indicating that there was no anxiety and depression among the present study participants.

According to SF-36 scores, score of mental health was negatively correlated to scores of HADS, for both anxiety (r=-0.523, p=0.013) and depression (r=-0.509, p=0.016). Participants with moderate-to-severe pain with an NRS of 4 to 10, exhibited significantly lower general health (GH) scores compared with those of participants with no-to-mild

#### Table 1. Demographic data (n=22)

Characteristics	n (%)
Sex	
Male	15 (68.18)
Female	7 (31.82)
Age (years): range 18 to 80	
18 to 40	5 (22.73)
41 to 60	7 (31.82)
>60	10 (45.45)
Education	
Lower than bachelor's degree	12 (54.54)
Bachelor's degree	8 (36.36)
Higher than bachelor's degree	2 (9.09)
Monthly income rank (Thai Baht)	
<5,000	8 (36.36)
5,000 to 10,000	5 (22.73)
10,000 to 30,000	5 (22.73)
>30,000	4 (18.18)
Marital status	
Single	5 (22.73)
Married	15 (68.18)
Divorced	2 (9.09)
Primary caregiver	
Self-care	3 (13.64)
Spouse	9 (40.91)
Parents/Children	8 (36.36)
Others	2 (9.09)
Period after amputation	
3 months to 1 year	9 (40.19)
1 year to 5 years	5 (22.73)
>5 years	8 (36.36)
Prosthetic limb	
Yes	14 (63.64)
No	8 (36.36)
Pain score; median (interquartile range)	
Minimum	1 (0 to 3)
Maximum	5 (3 to 10)
Average	3 (1 to 5)
Pain characteristics	
Phantom pain	12 (54.55)
Stump pain	11 (50.00)
Number of comorbidities	
None	5 (22.73)
1 to 2	8 (36.36)
>2	9 (40.91)
Cause of amputation	
Peripheral vascular disease	11 (50.00)
Trauma	4 (18.18)
Tumor	4 (18.18)
Others	3 (13.64)
Current analgesics	04 (05 (5)
Gabapentinoids	21 (95.45)
Tricyclic antidepressants	4 (18.18)
Serotonin-norepinephrine reuptake inhibitor	2 (9.09)
Tramadol	12 (54.55)
Strong opioids	4 (18.18)
Others: acetaminophen with codeine, eperisone, clonazepam	7 (31.82)

#### Table 2. The SF-36 scores

Domains	Mean±SD	Median	Min-max
Physical component summary	26.36±15.27	22.50	8.75 to 65.00
Physical function	23.86±18.70	22.50	0.00 to 60.00
Role physical	21.59±35.60	0.00	0.00 to 100.00
Bodily pain	16.36±10.93	15.00	0.00 to 40.00
General health	43.64±16.34	42.50	20.00 to 75.00
Mental component summary	68.02±16.45	69.80	35.94 to 96.25
Vitality	62.05±15.63	60.00	35.00 to 90.00
Social functioning	77.18±23.54	78.13	25.00 to 100.00
Role emotion	62.12±41.53	66.67	0.00 to 100.00
Mental health	70.73±16.58	70.00	40.00 to 100.00
Average SF-36 scores	47.19±10.07	47.10	27.83 to 67.50

SF-36=short form-36 health survey; SD=standard deviation

pain with an NRS of 0 to 3, which were 35 (IQR 25 to 40) and 45 (IQR 40 to 55), respectively (p=0.039).

#### For qualitative data

After being selected, some participants were unable to participate. Subsequently, nine participants were invited and groups of four to five participants were established by convenience. After group discussion, one participant was excluded because his pain was in his amputated arm, not his amputated leg. Finally, the authors analyzed data from eight participants who took part in the group discussion and individual interviews to reflect the multidimensional impact of lower limb amputation on QoL. Demographic data of the participants included in the group discussion and interviews are shown in Table 3.

The diagram in Figure 3 shows five themes that emerged in the investigators' meeting, as discussed below.

#### **Biopsychosocial effects of amputation**

**Biological effects**: All participants were able to maintain normal daily activities, except high-intensity tasks.

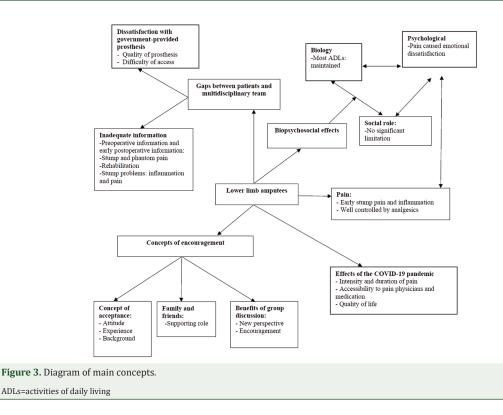
"I do my daily activities all by myself. I use a walking frame in my house and wear a prosthetic leg when going out. I had some areas of my house renovated, such as my bathroom, to be more suitable for me. I can drive but I had to stop my regular dancing and golfing." (Patient 2)

"I can drive to the university. I hang out with friends as usual because they understand and encourage me. Limb amputation decreases my confidence regarding relationships with male friends. Before becoming an amputee, I used to surf and swim, but I quit those activities recently." (Patient 8)

Table 3. Demographic data of participants for group discussion and interviews

Patient ID	Age	Sex	Occupation	Amputation level	Time since amputation	Reason for amputation	Previous amputations
1	68	М	Retired military officer	Rt AKA	12 years	PAD	No
2	68	М	Business owner	Lt hip disarticulation	9 years	Myxofibrosarcoma	No
3	56	F	House maid	Rt BKA	3 years	Chronic wound from diabetes mellitus	No
4	61	М	Barber	Rt BKA	7 years	PAD	No
5	58	М	Pharmacist	Rt AKA	12 years	PAD	No
6	68	М	Self-employed	Rt AKA	52 years	Trauma	No
7	81	F	Housewife	Lt AKA	3 years	PAD	No
8	21	F	University student	Rt AKA	2 years	PAD	No

M=male; F=female; Rt=right; Lt=left; AKA=above knee amputation; BKA=below knee amputation; PAD=peripheral vascular disease



**Psychological effects**: Pain was reported to cause emotional dissatisfaction, and uncontrollable pain caused resentment for some participants. In contrast, pleasure was experienced when pain was controlled. Taking a large amount of medication was reported by some participants.

"I take a great number of medicines. However, it doesn't make me feel irritated because the pain is finally controlled." (Patient 2)

"Before my primary doctor referred me to the pain clinic, I had suicidal thoughts because of severe intolerable pain. But now I feel better after the pain is controlled. Recently, I have stopped doing activities when the severe pain comes up and morphine syrup diminishes the torture." (Patient 7)

**Social role**: Amputation initially limited social activities for some participants. However, over time, some amputees adjusted their social lives, and these limitations were less significant, enabling them to engage in social activities and roles in their lives.

"Retiree friends and I can travel to many regions of the country by plane. I wear my prosthetic limb while travelling and it is fine." (Patient 6)

"My daughter takes me to funerals, wedding ceremonies, graduation ceremonies, and Buddhist charity events by wheelchair." (Patient 7) "I choose to only engage in essential social events because I worry about being a burden. I avoid any overnight events." (Patient 1)

#### Pain among amputees

**Early stump pain and inflammation**: All participants complained of stump pain, and some participants complained of stump inflammation in the first 6 to 12 months. On average, prosthetic limbs were used after the first year.

"I could not use a prosthetic leg in the first year due to stump pain. Many years later, I have become used to the prosthetic limb. Recently, I have been able to walk with a prosthetic limb for 30 minutes as exercise." (Patient 2)

"I started to use a prosthetic leg after the first year because of a stump wound problem. I have used three prosthetic legs due to the stump size changing as the swelling reduced." (Patient 3)

Well pain controlled by medication: Medicine was the most crucial factor controlling pain. Activities and positions aggravated pain for some participants. The role of alternative medicines was limited.

"Walking for long periods can exaggerate pain. I have never tried any alternative medicine." (Patient 6)

"I am not worried about using opioids and I can still cut customer's hair because of my expertise. I usually take morphine syrup four times per day, but have never tried alternative medicine." (Patient 4)

"Morphine syrup reduces severe pain but I feel drowsy. For mild to moderate pain, I choose paracetamol with codeine instead. Cooking can distract me from the pain so I feel it less. Nighttime and cold weather exaggerate the pain. Acupuncture does not help, whereas Thai massage helps me to relax for 3 to 4 days." (Patient 7)

## Concepts of encouragement in life

Acceptance concept: Concepts of encouragement differed according to different attitudes, experiences, and backgrounds. Some amputees reported finding ways to live with their changing conditions.

"Although this thing happened, life had to go on. We do what we should do in life. Tammy Duckworth is a Thai-American politician and a retired US army officer. She is the first Thai-American woman with a disability elected to Congress and the first female double amputee in the Senate. I am inspired by Tammy." (Patient 2)

"I encourage myself. I do not want sympathy from others. Youtube channels provide entertainment

and relaxation." (Patient 4)

"Previously, I suffered and lost self-confidence. After that, I let go of my suffering and encouraged myself. Now, if catastrophic thoughts emerge, I try to shut them up suddenly because I know nothing can be changed." (Patient 8)

**Family & friends**: Family and friends played a major supporting role for most participants. Some participants were concerned about being a burden to their families and friends.

"First, I was concerned about being a burden to my daughter. Then she encouraged me to accept things that could not be changed. Nowadays, I am satisfied that I can take care of myself." (Patient 3)

"Before amputation, I used to look after my 100-year-old dad and 84-year-old husband. I felt anxious about the changing situation. Anyway, my youngest daughter brought the three of us to stay at her home. My grandchild teases me, which makes me happy and cheerful." (Patient 7)

"I can take care of myself. Anyway, my wife always helps by taking part in activities that I cannot perform completely." (Patient 5)

**Benefits of group discussion**: New perspectives emerged among participants during the group discussion. Participants shared their experiences since becoming amputees. In addition, the interviewers observed encouragement between participants.

"I have never known about other causes of amputation before. It gives me a new perspective and a feeling that I am not suffering alone." (Patient 4)

"I have heard about life after amputation. Group discussion helps me a lot because, previously, I could not imagine what my future would be like." (Patient 8)

# Gaps between patients and multidisciplinary team staff

**Inadequate information**: Many participants faced severe pain before it was controlled and tended to feel insecure and hesitant. Insufficiency of the provided information was mentioned by many participants, reporting that they needed more information and suggestions about how to live as amputees.

"After amputation, I was faced with severe phantom and stump pain. Nobody provided information about my postoperative phantom and stump pain. I felt insecure and hesitant before the pain was controlled." (Patient 5)

"I felt anxious about stump and phantom pain because of the long time it took before the pain was controlled. I was also concerned about side effects from medicines, such as morphine syrup. Then, the doctor provided me with more information so I felt better and more secure." (Patient 1)

**Dissatisfaction with government-provided prosthesis**: Most participants reported difficulty accessing the prosthetic limb service, which was described as having an excessively long waiting time. In addition, the quality of prostheses was reported to be poor. Subsequently, most participants paid for prosthetic limbs from other companies.

"It is inconvenient because the prosthetic center is outside the hospital. The waiting time for prosthetic limbs is about six months or more. The equipment is made of wood, which is too heavy." (Patient 5)

"When I arrived at the prosthetic center, I found that, to get my prosthesis, the waiting time was longer than six months. A sales representative approached me. Finally, I decided to pay for my prosthesis by myself and I was happy that I got a high-quality prosthesis." (Patient 6)

#### Effects of the COVID-19 pandemic

**Intensity and duration of pain**: For most patients, intensity and duration of pain were not affected by the COVID-19 pandemic. Some participants reported new musculoskeletal pain which increased using of non-opioid analgesics.

"During the pandemic, my pain did not change much, but I felt more stressful and anxious from restriction protocols during lockdown." (Patient 1)

"I cannot go to gym as usual and exercise at home did not work out. I developed more muscle stiffness these days. Then, I try to do more stretching exercise and pain was also reduced with paracetamol and diclofenac." (Patient 8)

Accessibility to pain physicians and medication: Most participants did not have difficulty accessing to pain physicians and medication. They were able to reach the doctors by phone and would have ongoing access to medication.

"Although, the hospital had limited their health services due to the pandemic, I could reach my pain doctor by phone and the clinic offered telemedicine. My medications were sent directly to me." (Patient 3)

"The pain doctor called me and asked how my pain was. It was good that telemedicine was existed, though morphine syrup was not allowed to be sent and I had to get it from hospital." (Patient 4)

**Quality of life**: Stress and anxiety from "lockdown" decreased QoL in most participants. Some of them felt depressed from restrictive measures (lockdown). "During the lockdown, I could not work because barber shop had to close. It was quite stressful cause we did not know how long the pandemic would last." (Patient 4)

"I was depressed as I had to stay only at home. My children and relatives dared not come to visit me because the virus was highly contagious, and they were afraid they could unintentionally transmit it to me." (Patient 5)

# Discussion

In a previous study, SF-36 PCS and MCS scores were found to be lower for amputees when compared to those of general population<sup>(3)</sup>. The current study showed that average SF-36 of the study participants was low. However, SF-36 MCS score was higher than SF-36 PCS score, implying that although the participants had functional limitations, they might be able to cope well and adapt themselves to overcome problems, particularly for psychosocial aspects.

The mean HADS scores of participants in the current study were lower than 11 for both the anxiety and depression scales. Thus, these two conditions were not indicated among participants. This finding may have resulted from good pain control, good adjustment, and coping skills, decreasing the levels of anxiety and depression in the present study participants. The results agreed with those of a previous study that compared HADS scores between amputees with PLP and patients with non-phantom chronic pain. The HADS scores, both anxiety and depression, were found to be lower in amputees with PLP group<sup>(6)</sup>.

The authors examined whether demographic characteristics affected SF-36 scores, revealing those participants with moderate-to-severe pain had significantly lower scores in the general health domain. This finding is comparable with the results of a previous study reporting that PLP and residual stump pain were found to be the predictive factors of QoL in lower limb amputees. The presence of PLP affected the QoL on physical health component more negatively than the mental health component<sup>(3)</sup>. This finding highlights the importance of treating chronic PLP and stump pain effectively.

Five main themes emerged in the qualitative data analyses in the current study, they are biopsychosocial effects after amputation, pain among amputees, concepts of encouragement in life, gaps between patients and multidisciplinary team staff, and effects of the COVID-19 pandemic.

All participants in the current study were able to maintain normal daily activities, except for highintensity tasks. A previous study reported that, in the daily activity subdomain, mobility and housing were reported as the lowest levels of performance at all evaluation times<sup>(25)</sup>. Among individuals with lower limb amputation, social role life habits are more disrupted than those associated with activities of daily living<sup>(25)</sup>. Previous studies have reported the impact of chronic pain on all aspects of QoL when pain is not effectively managed and cured<sup>(26)</sup>. According to the current results, physical and social roles were not disturbed when pain was well controlled, with proper adjustment and coping skills. Importantly, pain was reported to directly affect emotion. Thus, effective pain control is very crucial.

All participants reported experiencing pain and inflammation of the residual limb in the first six months to one year after amputation, which hindered their use of prostheses. Previous studies reported that the incidence of stump pain can be as high as 74%, persisting for years in approximately 10% of cases<sup>(27,28)</sup>. Stump pain can be classified into postsurgical nociceptive, neurogenic, prosthogenic, arthrogenic, ischemic, sympathetic maintained, referred pain from spine and joints, or pain that is secondary to abnormal stump tissue such as adhesive scar tissue or heterotopic ossification<sup>(29)</sup>. Acute stump pain is usually bothersome after amputation but is typically expected to resolve in the first week. The capability to walk with a prosthesis provided the significant impact on QoL<sup>(4)</sup>. This suggests that stump pain should be treated immediately and effectively so that patients can start using prostheses and return to their normal activities as quickly as possible.

Problematic pain symptoms, particularly residual limb, phantom limb, and back pain, affect most prosthetic limb users and have the potential to severely restrict participation in life activities<sup>(4)</sup>. A previous study at the Ramathibodi pain clinic revealed that chronic PLP and stump pain can be treated effectively with oral medication such as gabapentinoids, tricyclic antidepressants (TCAs), and tramadol, without any severe adverse effects<sup>(17)</sup>. This is consistent with the current findings that participants' average pain score was reported at mild level of 3/10, and oral medication was the most crucial factor to control lower limb phantom and stump pain. However, back pain was not mentioned by participants in the current study.

Despite their body image changing, it has been reported that lower limb amputees are able to maintain positive self-esteem with important effects of social resilience factors, including prosthesis, occupation, rehabilitation, psychological support, and encouragement from family and friends<sup>(30)</sup>. Individuals with positive self-respect tend to experience more happiness, optimism, and motivation. In the current study, some participants reported positive ways of living with their changed condition.

A previous study reported that patients who described their families as being supportive exhibited significantly less pain intensity, less reliance on analgesic, and better activity levels<sup>(31)</sup>. This finding is in accord with the current results from the participants who reported significant supportive roles of family and friends. Frontline practitioners should consider that chronic pain is associated with functional limitations related to positive and negative reinforcement from the family dynamic in response to pain<sup>(32)</sup>. It has been shown that treatment outcomes are improved when family members are involved in the process of treatment and pain education. It is also important to encourage communication between them<sup>(31,32)</sup>.

Pain is defined as "a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive, and social components"(33). This has increased acknowledgement and application of the biopsychosocial model. It indicates that social factors, such as social support have a key role in modulating the experience of pain in both clinical<sup>(34)</sup> and experimental settings<sup>(35)</sup>. This model shows the advantages of group discussion, which improves pain experience and social support. In group discussion, participants can share positive attitudes, methods for adjustment, concepts of encouragement in life, and coping skills. In addition, group discussion enables participants to feel less loneliness, and less different to others. Thus, group discussion among patients with similar diagnoses should be promoted because it can be particularly beneficial for patients experiencing difficulty adjusting or those whose conditions have recently emerged.

Gaps between amputees and treatment team staff were identified in the current study. Participants reported that they received inadequate information regarding pre- and post-amputation management. A participant mentioned that he felt more secure and confident to take pain medicines when the pain specialists provided him adequate information on pain management. Consequently, it may be beneficial for patients to have greater access to information about post-amputation pain, rehabilitation, and life as an amputee, so that they can prepare themselves better, both physically and mentally. In addition, dissatisfaction with prosthetic limbs provided by the government was also reported. Some participants reported that prostheses were of poor quality, and some experienced difficulty accessing prostheses. In addition, some participants reported receiving a prosthesis that was not the correct size or was excessively heavy. These factors are known to influence patient satisfaction with a prosthesis<sup>(36)</sup>. Thus, improving communication of clinical knowledge about pain and other issues to help amputees in their new lives, as well as improving the process for accessing a quality prosthesis, are important for addressing these gaps.

Effects of the COVID-19 pandemic was also explored. It has been expected that the COVID-19 pandemic and associated lockdown restrictions would impact chronic pain patients' QoL. For the first wave of the COVID-19 pandemic, the Thai government issued lockdown to take effect from mid of March 2020. Lockdown measures, being implemented in varying degrees throughout the country, were ended in mid of June 2020. Studies showed the same results as the current study that most participants' QoL was affected from lockdown condition, including social and physical distancing measures<sup>(37-39)</sup>. They encountered stress and anxiety from their living conditions, which was not knowing how long it would last. Some were depressed from isolation precaution. However, their pain did not changed much in terms of intensity and duration. New musculoskeletal pain was reported and self-managed. Obviously, telemedicine was the cornerstone of chronic pain management during the pandemic. It was brought to the forefront of patient care and accessibility of the treatment.

#### Limitation

The present study has limitations. The sample size was too small for quantitative data analyses, so it was not possible to compare the present study participants' scores of SF-36 and HADS with those from the previous studies<sup>(20,40)</sup>. In addition, the authors organized the group discussion and individual interviews by convenience. This may have led to selection bias and reduced reliability, potentially influencing the study results. However, credibility could be risen as the authors could provide prolonged engagement with the participants. Additionally, conducting repeated focus group discussion and interviews to increase credibility in the present

study could be difficult due to effects of COVID-19 pandemic during the period of data collection.

Focus group discussion enables participants to share experiences, encourage each other, and generate ideas and attitudes. However, this approach can lead to information not being revealed because of unfamiliarity among participants, differing personalities, or participants' seeking to maintain their social image. In addition, the use of retrospective data among participants who have experienced pain for a prolonged period means that they may not have detailed memories regarding pain experiences in the early stage and may tend to forget the suffering.

The present study did not include methodological triangulation, which may make results less reliable. In addition. the small sample size made it challenging to determine if the data were saturated. However, the authors did not discover any new concepts emerging from the individual interviews. Consequently, the authors considered that data saturation was achieved. Future studies may benefit from a larger sample size. Then, combined with quantitative methods, qualitative research can provide a complete picture of QoL in this subpopulation.

#### Conclusion

Lower limb amputees reported a low QoL. Amputation restricted patients' physical function. However, participants reported that pain management was a crucial factor, helping them to accept their condition and cope more effectively when pain was controlled. In addition, positive self-esteem and support from family and friends played a leading role in reducing psychological and social problems. Inadequate communication regarding information that is useful for amputees and prosthesis-related problems were identified as the main gaps that should be corrected. QoL among lower limb amputees was also affected by the COVID-19 pandemic, particularly lockdown measures. Fortunately, the level of pain was not changed, and telemedicine could continue the availability of chronic pain management.

#### What is already known on this topic?

Postamputation pain and changes of body image had a profound impact on amputees' wellbeing. To improve QoL of the amputees, previous qualitative studies alerted health care professionals to provide appropriate information and management of postamputation pain, empower amputees to acquire their right of independence, and pay more attention to their needs and support systems.

## What this study adds?

QoL in lower limb amputees was low, remarkably due to restricted physical function. Inadequate useful information for amputees and prosthesis-related problems still existed. This study emphasized that good pain control would play a vital role to help amputees start using prosthesis and return to normal life. The pain management was an essential factor, helping them to accept their condition and adjust lifestyle effectively. Despite lockdown restrictions during COVID-19 pandemic, telemedicine could maintain the availability of the pain management among lower limb amputees.

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## **Conflicts of interest**

The authors declare no conflict of interest in this work.

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