



Charles Sturt
University

Living with Pain: An Evaluation Report of the Wagga Wagga Red Cross Project for Humanitarian Migrants who Live with Pain

A Commissioned Report by the Australian Red
Cross

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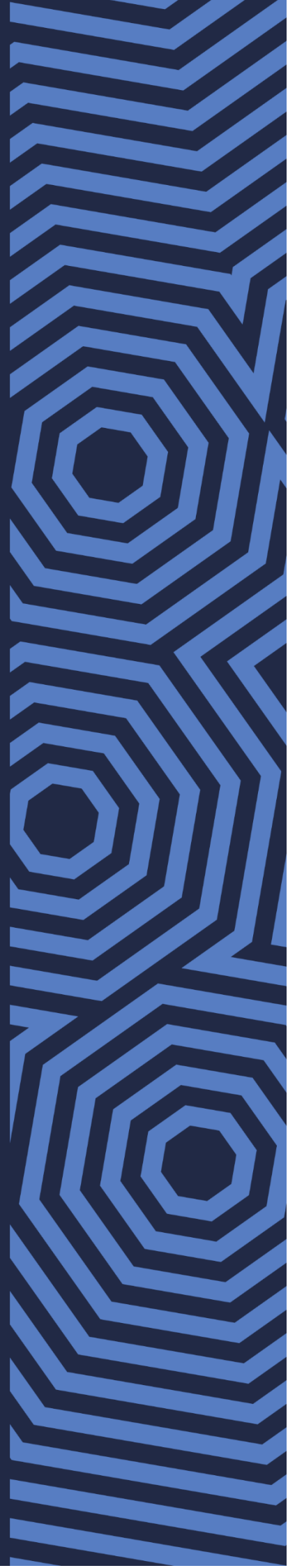
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Living with Pain: An Evaluation Report of the Wagga Wagga Red Cross Project for Humanitarian Migrants who Live with Pain

This report was commissioned by the Australian Red Cross (Red Cross). The Red Cross approached Charles Sturt University (CSU) to evaluate a project conducted in Wagga Wagga (NSW, Australia) for humanitarian migrants who live with chronic pain.

Contributions:

Both authors were involved in the evaluation design, data analysis and writing of this report.

Dr Skinner conducted the interview with the Physiotherapist, both authors conducted the focus group with facilitators, and Dr Freire conducted the interviews with the participants (ladies).

Ethical Approval:

Ethical approval was granted to conduct this evaluation study by the Charles Sturt University Human Research Ethics Committee. HREC approval number H21030.

Author Conflict of Interest Statements:

Ian Skinner has no conflicts of interest related to the project.

Kate Freire has no conflicts of interest related to this project.

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- *F1* and *F3* for assistance with contacting the ladies for interviews and for translating during the interviews.
- *F2* for her assistance in providing background information on the project, facilitating the completion of the questionnaires and generally supporting the evaluation.
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Executive Summary

The aim of the Australian Red Cross Living with Pain Project was to assist humanitarian migrants living in the Wagga Wagga area who live with chronic pain.

The project that was evaluated consisted of fifteen sessions. Seven sessions were part of the initial group formation, and eight sessions has a specific focus on pain education and general management. Of the eight sessions focuses on pain, four were conducted by a *Physiotherapist* on a fortnightly basis with four reflection sessions interspersed on the alternating weeks.

The sessions were conducted at the Red Cross in Wagga in person.

The ladies who took part in the project were humanitarian migrant Yazidi women living in Wagga Wagga in NSW Australia. Fourteen women registered to take part in the project. The women spoke little to no English and a translator was required for all the sessions and the interviews as part of the evaluation.

Ten ladies from the project were involved in the evaluation of the project and took part in an interview to provide feedback on their experience in the project.

A focus group and interview were conducted with the five facilitators of the project and the Physiotherapist who provided the specific pain sessions.

The data from the interviews and focus groups was analysed by two researchers who wrote this report.

Eleven key themes were identified from the interviews with the ladies:

1. My mind is elsewhere
2. We can't forget our pasts
3. Not remembering
4. Peacocks and lions
5. Headaches and migraines
6. Shifting focus
7. Role of medications
8. Making friends
9. Expectations should be addressed prior to group attendance
10. The group should be about more than pain
11. Group context

Four overarching themes were identified from the analysis from the facilitators' focus group and Physiotherapist's interview. Within each of the four themes there were multiple subthemes:

1. Social aspects of the group
 - 1.1. Social Connections: It's a place that's providing a social ground for them
 - 1.2. Attendance: we don't know what's happened in their world
2. Learning
 - 2.1. Group Formation- A Tangible Hook
 - 2.2. Development of teaching materials- "We don't know, you tell us"
 - 2.3. A cultural Lens: "Make it as relevant and culturally sensitive as possible"
 - 2.4. Location of Sessions: "A SAFE SPACE"
 - 2.5. Language barriers: keep the language quite simple and chunk it down
 - 2.6. Reflection Sessions: That was really helpful
 - 2.7. Experiential Learning for active strategies: "letting them touch and feel or experience"

3. Making sense of pain
 - 3.1. Making sense of their Pain: not as tainted by a bio-medical model
 - 3.2. Behaviour Change and Management Strategies: did it change once they left the room
4. The impact of trauma
 - 4.1. Past traumatic experiences: It came up every session

The researchers used the findings from both the ladies and facilitators to develop eleven key recommendations for the Red Cross to assist in the design and planning of future projects:

1. To encourage participation and manage expectations, a clear outline of the project schedule should be presented to participants prior to commencement of the project
2. Recognise that participants are keen to commence pain management strategies as soon as possible.
3. Consider grounding the project within an educational paradigm
4. Recognise it may be easier for participants to provide feedback on a draft plan of topics.
5. New ideas take time to learn, thus, repeated opportunities and fun ways to learn new things should be provided.
6. Education about pain and its management should be presented in small doses and as experientially as possible.
7. Recognise the learning difficulties and limited practice opportunities that refugees encounter.
8. Recognise participants varying capacity to talk about the past.
9. Gain feedback at the end of each session to overcome the memory issues of the group members.
10. The group should be about more than pain education
11. A consistent space should be used for the location of the group

In addition, six key messages for the ladies were developed to reinforce ideas that were presented during the project and based upon their feedback.

The impact of Covid-19 meant that a participant feedback session for the ladies was not completed. The researchers had planned to travel to Wagga to present the initial findings to the ladies, and seek their feedback, however travel was not possible for when this was planned.

The report is presented in the following order: recommendations, background to the project, an overview of the project, the methods that were used to conduct the report, and finally the themes identified from the data that were used to determine the recommendations.

Key Recommendations for Australian Red Cross and Facilitators

1. To encourage participation and manage expectations, a clear outline of the project schedule should be presented to participants prior to commencement of the project

There needs to be a clear hook at the start of the project to help paint the vision of the group and gain buy in from the cohort. Clear expectations and structure are important to avoid participant disappointment. In conjunction with a clear structure for the group, there needs to be a clear evaluative plan to determine if the project resulted in behaviour change. Due to the language barriers the evaluative tools need to be easy to implement and currently tools that assess the potential mediators of attitudes and beliefs are difficult to interpret for non-native English speakers.

2. Recognise that participants are keen to commence pain management strategies as soon as possible.

Active management strategies, such as yoga sessions, could be incorporated into future projects, as part of the group formation sessions. These sessions could then be integrated throughout the project as examples of activities that may be helpful.

3. Consider grounding the project within an educational paradigm

Establishing clear learning outcomes and a strategy to achieve each outcome will allow greater transparency of the project's aims and effectiveness to all stakeholders. Identification of learning outcomes will also allow discussion with the community to ensure that all presented material is culturally safe and appropriate which will enhance the participants' learning experience.

4. Recognise it may be easier for participants to provide feedback on a draft plan of topics.

Inviting participants to critique a prototype or plan is easier than inviting ideas or views without a reference point. The pain revolution target concepts present a good foundation for potential topics that could be covered but those concepts that aren't appropriate to a culture's worldview should be adapted or omitted. However, it should be acknowledged that those concepts were developed for a Western audience. Future projects should consider co-development of the content and the presentation of the content between members of the relevant community before the project commences to ensure the content is culturally appropriate and specific to the audience. For example, building in specific references to the effect of trauma would be appropriate. In addition, build opportunities for participants to suggest future topics into the project as it is being delivered.

5. New ideas take time to learn, thus, repeated opportunities and fun ways to learn new things should be provided.

The consolidation sessions between pain education sessions were helpful to review and revise knowledge. Where possible, ideas should be introduced to participants using references that they can relate to. Metaphors are a powerful way to present challenging and complex ideas. The metaphors need to be culturally appropriate to ensure they make sense to the target audience. Non-abstract visual images are another important way to assist in understanding of the content. Due to the limited time available each session, the key themes and take away messages should be short and clear. They should be presented at the beginning and end of the session.

6. Education about pain and its management should be presented in small doses and as experientially as possible.

The content of each session should be no longer than 15 minutes in duration to allow time for translating and repeating of key themes and to allow time for questions. Education should be paired with experiential learning activities that link to the themes being delivered. Practical activities help participants develop their skills, in addition to their knowledge about pain. Both are important in pain management. Recognise the importance of using interactive activities to enable greater engagement and possibly retention of material, with populations where memory may be poor. Recognise that providing experiential learning activities that are also run in the community may encourage participants to join these activities and broaden their engagement with their local community as well as their activity levels.

7. Recognise the learning difficulties and limited practice opportunities that refugees encounter.

Provide participants with opportunities to practice their English. Advocate for longer support to learn English.

8. Recognise participants varying capacity to talk about the past.

Each group session should begin with a brief discussion about what everyone is comfortable to talk about today. It should be acknowledged that this might change from day-to-day, but it is up to group members to ensure that they consider and look after everyone in the group. Consideration should be given about the appropriateness of a group project for participants who have experienced trauma and in which that past trauma is likely to be a topic of conversation related to the theme of the group. If a group project is utilised, there should be multidisciplinary shared session of impact focused on past trauma which is delivered by an expert in trauma. Specific strategies are needed to deal with past trauma in a culturally safe way for all participants. These could include having a psychologist run the sessions side by side with a pain specialist.

9. Gain feedback at the end of each session to overcome the memory issues of the group members.

Try to gain feedback in different ways: e.g. ask group members to vote on their favourite bit of the session. On the way out of the door ask them to tell you which what they liked most about today and what they liked least. This will encourage group members to take some ownership of the group. It will empower group members (if you act upon their feedback) and give them a voice.

10. The group should be about more than pain education

Pain is influenced by all sorts of things so the group activities should be broad. This will help participants see that other things that improve their life can also improve their pain. Participants are focused on gaining English language practice opportunities and learning more about living in Australia. Every session with participants should (near the beginning) incorporate opportunities for practising their verbal English skills.

Other ideas to incorporate in the group:

- Add in a "tip" or advice of the week.
- Encourage group members to contribute and have a voice, e.g. Go around the room asking them each to recount something that has given them joy this week.
- Access to certain services/ tips for accessing.
- Other things happening in the community/ TAFE
- Cooking recipes/ tips

11. A consistent space should be used for the location of the group

The space should offer a feeling of safety. Consideration could be given to the way the room is set up and decorations or ornaments that assist in making the participants feel relaxed and comfortable to share their thoughts and feelings and learn in a non-threatening environment.

Key Messages for Participants

- 1. Because you are thinking about other important things in your life it can be hard to learn new things.**
- 2. You have been through tough times and stress can affect our memory. But it is important for your brain health that you are trying. Well done, keep going.**
- 3. Some of you do not want to talk about the past but some people do want to talk about their past.**

This can make it hard for some people to come to the group. We suggest that at the start of each group session the group agrees upon whether they are comfortable to reminisce about the past; and what they feel comfortable discussing that day. This approach acknowledges that everyone's tolerance for discussing the past will vary from day-to-day.

- 4. Relating your learning to something that has special meaning to you, or your culture, is a good way to learn.**

- 5. Learning by doing is a good way to learn.**

The peacock and lion activity showed you all that you can learn new ideas. [Name of physiotherapist] related this idea to something that had special meaning to you and gave you an activity to do which also helped you to remember. It's a good way to learn! Try to find other ways of learning by doing as well. Practical activities can be used to help learn new information and develop skills to help with pain.

- 6. Medications can do lots of things and it is important to know when medications are helpful and what they are for.**

Understanding your health and what is being done for your health are important so that you can make informed decisions and be active participants in your healthcare.

Background

The rate of chronic pain in resettled refugees is three times higher than the rest of the population with 30% of all resettled refugees experiencing chronic pain^{1,2}. Up to 83% of refugees who have been tortured experience chronic pain³. At least 40% of refugees are resettled in regional areas of Australia placing a significant burden on regional health care services⁴. Managing pain in refugees is complex due to previous experiences with health care workers, language barriers, and traumatisation⁵.

Chronic pain in resettled refugees is complex and is often experienced alongside indicators of psychological distress including post-traumatic stress disorder, depression, anxiety and stress^{6,7}. In addition resettled refugees face challenges relating to a diminished sense of identity and isolation that negatively affects their health⁸. Previous studies based in Australia have reported that access to health services is crucial to resettlement⁹, and that high levels of depression are common, more so in women, and are associated with isolation and physical inactivity¹⁰.

Current best practice pain management programs that use a cognitive behavioural therapy (CBT) approach demonstrate small effects at improving pain¹¹. In survivors of torture limited evidence indicates CBT is not effective at decreasing pain¹². Guideline care encourages a multidisciplinary approach with a focus on pain education and physiotherapy combined with cognitive and behavioural interventions in an individual or group setting¹³.

Community health programs are effective for promoting health in refugee communities and increase a sense of belonging and unity through collective community action^{14,15}. It is not known if community programs are effective in improving the quality of life in refugees who experience chronic pain in regional Australia. It is also not clear how pain programs need to be adapted for humanitarian migrants who experience chronic pain.

In March 2020, Wagga Red Cross identified that a large percentage of their clients were experiencing some sort of persistent or recurring pain which affected their participation in activities and integration into the local community. Establishing a group to support those that have pain led to the development of the 'Living with Pain Project'. An interdisciplinary Steering Committee was set up to drive the project and ensure the provision of safe and accurate information to the group around the topic of pain management, community development and humanitarian migration experience. Yazidi women were identified as a population group within Wagga that would benefit from the project and thus were invited to be the participants in the first iteration of the project.

Overview of the Living with Pain Project

Project Name: Living with Pain Group

Location: Wagga Wagga, NSW Australia

Target Audience: Humanitarian migrants who are experiencing persistent or recurring pain and are receiving/requiring treatment and support for pain management.

Project Goal: To develop a living with pain group for humanitarian migrants that are experiencing persistent or recurring pain in their everyday lives.

Desired Outcomes: For group members to receive strategies and skills to manage their pain through involvement in a group that supports these processes.

Outline of the Living with Pain Project

The project had two phases

Phase One: Formation of the group and group dynamics (seven sessions between October and December 2020).

SESSION #	DATE	CONTENT	No of Ladies
1	29/10/2020	Introduction of facilitator, BSW and of the 'Pain Group', Ice-breaker activity, Group agreement, Broad overview of upcoming sessions – including explanation of pre-evaluations	6
2	5/11/2020	Pre-evaluations	9
3	12/11/2020	Ice breaker activity – how their culture defines a woman. Culture of pain – What do you think is causing your pain, how does pain impact on your life, what would you like to know more about in relation to pain, what do you do when you have pain, what do you think will help your pain	4
4	19/11/2020	Ways of learning – How would the group like to learn? Styles of learning - Reading vs listening vs power point, vs open discussion vs experiential learning	9
5	26/11/2020	Mental Health awareness – What is Mental Health, Importance of Mental Health, Signs of not coping well, What to do when not coping well, Professional support and services available. Explanation of photo voice activity	5
6	3/12/2020	Photovoice facilitated discussion – What would you like to do or do more of, but can't as a result of your pain?	3

7	10/12/2020	Sleep - Types of sleep difficulty, why is it hard to sleep, importance of sleep, importance of sleep hygiene and sleep routines	10
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Phase Two: Four pain education and management strategies interspersed with three review sessions and one introductory session. There were therefore eight sessions in total for phase two (January 2021 – March 2021).

Session #	Date	Content	No of Ladies
1	28/1/2021	First session back after break. Revisit of group agreement. Specifically around 'disclosures' and being respectful of the whole group. Introduction of upcoming sessions with Kylie.	3
2	4/2/2021	Pain Session 1 – Why do we hurt?	2
2a	11/2/2021	Reflection session – Showed a pain science video. Feedback on whether they found the information about pain helpful (either last week session or in the video) Has the information made them think about pain differently?	3
3	15/2/2021	Pain Session 2 – Your over-protective pain system	6
3a	1/3/2021	Reflection session – Did they find the information about pain helpful? Was there anything in particular in the session that stood out to them or that they have thought about or used this week? Has the	3

		information made them think about pain differently?	
4	8/3/2021	Pain Session 3 – Danger and Safety, Lions and Peacocks	3
4a	15/3/21	Reflection session for session 4. Session cancelled due to only one participant being available.	1
5	29/3/2021	Pain Session 4 – Re-training the brain	3

The aim and objectives of the evaluation for the report to the Red Cross

Aim:

To evaluate a pain education group project that aimed to improve the health and wellbeing of humanitarian migrants living with chronic pain in regional Australia.

Objectives

The objectives of this research evaluation were to:

1. To evaluate a pain education group for humanitarian migrants living with chronic pain in regional Australia from the perspectives of the humanitarian migrants, the group facilitators and the pain educator.
2. To explore humanitarian migrants' experiences of taking part in a pain education group project in regional Australia.
3. To investigate the strategies and topics, from the perspective of group participants, facilitators, and pain educators, that were perceived to be effective for humanitarian migrants living with chronic pain who took part in a pain education group project in regional Australia.
4. To investigate if and how the perception and conceptualisation of pain changed in humanitarian migrants living with chronic pain who took part in a pain education group project in regional Australia.
5. To investigate whether there was a change in quality of life of humanitarian migrants living with chronic pain who took part in a pain education group project in regional Australia.

Methods

Research Approach

A mixed method design was used to provide as comprehensive a picture as possible. The intention was for quantitative health and wellbeing outcome measures to be assessed before and after completion of the project. In addition, interviews with project participants and the pain educator and a focus group for facilitators of the project were conducted.

Permission to conduct this evaluation was gained from Charles Sturt University Human Ethics Committee.

Terminology

A decision was made to use the term "ladies" when referring to the participants from the Living with Pain Group who took part in this study. The Red Cross facilitators referred to them in this way. All the participants in the study were female and we felt that the term ladies assisted in ensuring the human aspect of the people who experience chronic pain daily is not lost from the research.

When a direct quote from one of the ladies has been provided in the report an alias has been used to protect the identity of the participants.

When a direct quote from one of the facilitators has been provided in the report they have been referred to as F1, F2 etc.

Due to the unique level of knowledge and experience that the physiotherapist, who provided the pain education had, we felt it was important, with her permission, to identify her as a physiotherapist and not a facilitator. The physiotherapist had additional post graduate training for people with chronic pain. Therefore, when a direct quote is provided from the *Physiotherapist* we have indicated this after the quote using the term "*Physiotherapist*".

Participants

To be eligible to take part in this evaluation participants had to meet all the following eligibility criteria for one of these groups:

Group 1:

- A Yazidi woman who participated in the Australian Red Cross Living with pain project.
- Over the age of 18.
- There are no other exclusion criteria that were applied. It was anticipated that most of the women would have limited English literacy and would require an interpreter who was provided by the Red Cross.

Group 2:

- A facilitator who assisted in the design and implementation of the Australian Red Cross Living with pain project.
- The facilitator could have been an interpreter, a designated group facilitator, the *Physiotherapist* designed to provide the pain education and management strategies, or the project lead who was involved in the daily communication between the facilitators and the participants and making decisions as to the organisation of the group.

Quantitative Methodology

The quantitative methodology was designed to address objective five of the study- that being to determine if there was a change in the quality of life of the participants who took part in the project. Ethics for the evaluation of the project was obtained after the project had begun and thus for the evaluation, we were reliant on the information that had been obtained by the Red Cross before the project began. Information regarding demographics was collected by the Red Cross as well as information about the referral source. Participants also completed The World Health Organisation-Five Well-Being Index (WHO-5) and the World Health Organisation Disability Assessment Schedule (WHODAS 2.0).

The WHO-5 is a short self-reported measure of current mental wellbeing as experienced over the previous two weeks. There are five questions which are summed to give a score out of 100. A score of 100 represents the best imaginable well-being.

The WHODAS is a tool for assessing health and disability across cultures in terms of function. The simple method for scoring the WHOHAS 2.0 is to sum the scores for each item. The range of possible score is 12 to 60. A higher score indicates a lower level of function compared to a lower score.

Qualitative (Hermeneutic Phenomenology) Methodology

Recruitment

Both participants and facilitators were invited to take part in the evaluation of the project.

Participant recruitment

All participants who took part in the Living with Pain project were invited to take part in interviews. One of the researchers (KF) attended the final pain education session and provided an initial verbal briefing about the research which was translated by one of the Red Cross Facilitators. Participants of the project were then contacted by a Red Cross facilitator, informed about the evaluation, and invited to participate. They were provided with a participant information sheet and a

consent form in both Kurdish Kumanji and English. It was emphasised to participants that participation was voluntary, and that they were under no obligation to participate.

Ten participants participated in an interview.

Facilitator and Physiotherapist recruitment

All facilitators, including the pain educator, who took part in the Living with Pain project were invited to take part in a focus group and the pain educator was invited to take part in an interview via email. All facilitators (n = 4) and the Physiotherapist participated in evaluating the project.

Data collection

Data was collected between April and May 2021. The semi-structured participant interviews provided an opportunity to explore each participant's personal experience of the Living with Pain Project. The interviews were conducted in person by one of the researchers (KF) at the Red Cross Building in Wagga. The interviews were audio recorded. Red Cross facilitators agreed to act as translator for the researcher and were instructed as to the importance of translating verbatim so as not to change the meaning. We took this approach because it was felt that the facilitators already had the trust and connection with the community. However, as untrained interpreter's the facilitators were not consistent in their verbatim translation, interchanging between first and third person. We have not changed this in our analysis. Meaning was clarified during the interviews by paraphrasing the participants answer which enable deeper reflection. All participants were provided with a voucher (\$50) for a supermarket post-interview to thank them for their participation.

The facilitator focus group was conducted in a mixed setting with the facilitators and physiotherapist based in Wagga and the two researchers online via zoom at the completion of all the sessions. The focus group was audio and video recorded and transcribed verbatim by a third-party transcribing service. Due to logistics, KF led the facilitator focus group, with IS, on zoom, assisting with questions as necessary.

The physiotherapist interview was conducted online via zoom at the completion of all the sessions. The interview was audio and video recorded and transcribed verbatim by a third-party transcribing service. IS conducted the interview with the physiotherapist. The interview was based on the guide provide in Appendix 3 but also informed by feedback from the ladies' interviews and the facilitators' focus group.

Copies of the interview guides are in Appendix 1: Facilitators Focus Group Interview Guide, Appendix 2: Ladies Interview Guide, Appendix 3: Physiotherapist Interview Guide.

Data analysis

Transcripts of the facilitator focus group, and pain educator interview were sent via email to the participants for member checking. The intent was to present initial findings and gain feedback on our analysis from participants at a group morning tea. This was instead of traditional member checking due to the low level of literacy amongst participants, but after several cancellations due to Covid-19 lockdowns, this was abandoned.

The qualitative data was analysed within a hermeneutic phenomenological framework. Analysis involved two phases. Analysis of individual interview texts were coded according to the research questions and broad nodes identified. In the second phase of analysis, two transcripts were created by combining: (1) transcripts of all the participants of the Living with Pain project data, and (2) the Facilitator focus group and the Pain Educator interview. Themes and subthemes were identified by searching for similarities and duplicates; and then refined to form a more condensed and focused thematic analysis. The researchers met regularly during this time to enhance reflexivity through consideration of alternative perspectives and scrutinisation of decision-making.

The results of the analysis for the participants and the facilitators were grouped according to themes. Within each theme there were multiple subthemes. Each theme is presented in the results separately to enable equity in their voices.

The themes from the participants and the facilitators were then combined into recommendations for the Red Cross and also for the Participants. These are the recommendations at the beginning of the report.

Results

Quantitative Data

Of the ten ladies who consented to take part in the evaluation eight ladies completed the WHO-5 before the commencement of the project and six ladies completed the WHO-5 at the end of the project. Four of the ladies completed the WHO-5 at both time points.

Of the ten ladies who consented to take part in the evaluation seven ladies completed the WHODAS 2.0 before the commencement of the project and six ladies completed the WHODAS 2.0 at the end of the project. Four of the ladies completed the WHODAS 2.0 at both time points. Due to the low numbers of ladies who completed the questionnaires at both time points there is little value to be gained from comparing the pre and post evaluation scores. The pre and post scores for both the WHO-5 and the WHODAS 2.0 are presented below for transparency.

ID	WHO-5 Pre / 100	WHO-5 Post / 100	WHODAS Pre /60	WHODAS Post /60
1	56	44	19	42
2	36	56	35	51
3	16	8	23	17
4	28	0	31	42
5	40	ND	31	ND
6	60	ND	27	ND
7	44	ND	31	ND
8	84	ND	ND	ND
9	ND	8	ND	29
10	ND	80	ND	54

ND denotes 'no data' available

Qualitative Data

Qualitative Data from the Ladies

Eleven overarching themes were identified from interviews with the ladies:

1. My mind is elsewhere
2. We can't forget our pasts
3. Not remembering
4. Peacocks and lions
5. Headaches and migraines
6. Shifting focus
7. Role of medications
8. Making friends
9. Expectations should be addressed prior to group attendance
10. The group should be about more than pain
11. Group context

1. My mind is elsewhere

The ladies were generally more focused on factors other than their own current individual circumstances. They were concentrated upon their separation from their families and remembering their past experiences in their homeland.

"She's saying she's forgetting everything because ... because it's too much for her. She had been in ISIS' hands for two years and a couple of months. She doesn't know anything about her husband and her family is still in Iraq in a dangerous place, so she is not thinking about herself". Bryony

Thinking about family

They explained their persistent thoughts were about the members of their family that they were separated from because of their humanitarian migrant status. The ladies described how they had family members who lived in other parts of the world, including: Turkey, Germany, Canada, and Iraq. They told us how they missed them and worried about them. For example, Aster says, via the interpreter, she *"can't control her pain because she's thinking what about her children in Germany. Because she wants them to be here, but they are not here"*. Some ladies referred to their ongoing efforts to bring members of their family over to Australia and their difficulties with this process during their interviews. The ladies revealed that their family's plight meant that they found it difficult to shift their focus to other things.

"She said she doesn't have anything in her mind, just thinking about the family in Iraq, and they've been in a bad situation". Kalmia

Adding to these concerns, some ladies were still unaware of what had happened to members of their family. They pointed out that not knowing meant they could not name whether their pain was from separation or bereavement and there was a sense that not being able to distinguish their pain added to their distress. *"They keep thinking about what's going to happen to their husband, because they still with ISIS, and some of them, they have pain and they don't know what pain they have still". Iris*

I will feel better when my family is whole/together again

The ladies agreed that their family situations were a cause of their discomfort. For example, Iris says, *“When I think a lot about my mum, that she's sick, or her brother doesn't have children or she doesn't have her sister here, and she's by her own, I get pain”*. And a consensus that reuniting with their families would make them feel better. Kalmia says *“They will bring them here. That's going to help them to just remove their pain because they're thinking about their family and they're getting pain. So, when the family here, that will be helpful”*.

Their understandable focus on their family, and desire to gain help for their family, distracted their attention on the purpose of the interview and their ability to critique of the group.

“She's saying, nothing in [her] thinking, there is nothing that could be added to the group. The only thing is that she needs, she just wants to bring her children here”. Aster

2. We can't forget our pasts.

The ladies were also focused upon their own past experiences and the impact that had on their lives today. For example, Bryony says *“[She has] pain from that story, so this is the big, hard thing that [she] have”*. Bryony went on to describe how her past was impacting her present life and how she found it hard to discuss what had happened to her. She says *“Because for her, sometimes it is very hard for her to speak what she has in her head. Sometimes, she is saying, there is something that I can't say and it's still in my head and there is pain”*.

Some of the ladies described wanting *“to forget their thinking”* (Jessamine) and their distressing memories, whilst others found talking about their past helpful.

“She said just when we come and we are talking about like our past, what we've been through, so it was helpful to just reach out of everything from your heart”. Aster

Thus, getting the right balance in the group, between those needing to discuss their past experiences and those wishing to move on, was difficult and impacted group attendance of those women who did not wish to review their past experiences.

“One of her friends, she just attended one session, she think, and then she asks, “why you don't come?” and she said, “because sometimes they talk about something that makes me very sad and very upset and that is why I don't want to attend”. Bryony

But as Bryony went on to acknowledge sadness was close to the surface for these ladies and they also got upset without talking about the past.

“... but sometimes in the group, we were talking – like, we don't have to say something very sad to make other people upset”.

3. Not remembering

All the ladies complained about their poor memory and the impact that had on their everyday lives. Ladies linked their focus on their family separations and their past to their poor memory: *“She said I*

forget everything. ... Sometimes [her] brain just talk, doesn't work and she can't remember anything. Because she's thinking about her children in Iraq" (Laurel).

Ladies described how their memory issues impacted their re-settlement in Australia by impacting their ability to learn English and learn new information during group sessions, including the pain education sessions. For example, Myrtle says: *"The problem is [she's] not remembering that. [She] don't remember what she was discussing about".*

4. Peacocks and lions

Despite their memory and focus issues, many of the ladies were able to recall a particular session during the Living with Pain Group where they discussed features of their lives that might either reduce or increase their lived experience of pain.

"We have pictures like a peacock and lion and [name of pain educator] was saying that she bring lots of pictures, and Centrelink one, one of them too, and she said Centrelink is like peacock. She is giving me money so she's helping me. So she said, "I'm not going to forget that session". Hazel

As Bryony explained, the use of the peacock to depict an activity or thought that ladies could use to reduce their pain resonated with ladies because the peacock is significant in their culture and the Peacock Angel (Melek Taus) is a central figure in their religion.

"She is saying they are a good thing that she brings. The lion is like a dangerous animal and all of us are scared from the lions, it's the pain, but the peacock is nice and very friendly. Because in our Yazidi culture it's something special for us". Bryony

Many of the ladies described how they now used the idea of 'peacocks and lions' in their lives to control their stress and bring them into the present.

"It was good. When they're talking about when you're a little bit stressed you can go and cook or listen to music and dance to just forget your stress". Myrtle

In contrast, to the warm reception and positive active learning experience of the peacocks and lions' session, one participant, Celia described a negative experience in the group where she felt she was being misled¹.

Celsia: "They were teaching us - they were putting a photo on the screen. There was a lady wearing a dress. It was black and white and after they ask us "what is the colour" and everyone said "this is black and white" and they said "no, you are wrong. It is not black and white. It is black and another different colour." I get more mental health because they're putting me - the wrong thing. Even the interpreter, another lady from Red Cross was with us, and she said same like them. They told us "you are wrong" so even with this I get worse than before because even if have a mental health problem I have good eyes. I see the

¹ It was clarified after the analysis that this quote and the scenario described occurred during a reflection session where the physiotherapist with specialist pain training was not present.

colour. So the colour is not like the other that they said so for this reason it was worse for me”.

Kate: “I’m sorry to hear that. Were they trying to explain that sometimes our senses can play tricks on us? Was that what they were trying to explain?”

Celsia: “There was not any reason or any explanation for that. We thought maybe from afar we cannot see the colour but then we go to near to the screen and it was black and white but they told that it’s not. It was black and gold”.

Celsia was indignant when recalling her experience several weeks later. And the ladies interviews occurred after the focus group of facilitators’ so it wasn’t possible to gain further insights the facilitators thoughts about the session and their explanation about the fickleness of our senses.

5. Headaches and migraines

The ladies also spoke about the impact that headaches and migraines had on their lives and difficulties attending the pain group. However, this was generally mentioned later in the interviews once they had spoken about their experiences of family separation and their painful memories. These symptoms were mentioned infrequently compared to their frequent revisiting of their distressing family situations and traumatic memories.

“I just want to learn more about the pain because my pain is a big issue for me, especially the headaches. I’m having bad headaches and I want to know the important thing about how I can remove the pain and how I can forget my pain”.

Myrtle

Myrtle went on to say that she did not think the group would help her with these symptoms as she felt they required consultation with a specialist.

“The problem is that the group’s not going to help me. I want to know if there’s any advice or any special doctor for headaches. I just want to go. This has been four years. I just had medication and medication’s not helping me and my husband is sick and also my kids are sick too. ... I just want to know if there is any specialist that I can go to”. Myrtle

Ladies described how their symptoms impacted their attendance at the group.

“The challenge that she’s having, she’s been through her pain, like brain pain and also headache and vision. When she having a headache, she’s having eyes ache too. She couldn’t listen probably and she will have stomach ache again after that. So on that time, on that case, she cannot be able to attend the sessions”. Kalmia

They described what they did to manage their symptoms.

“She tries not to lay down because of her pain. She try to do some stuff at home, even her homework. But when the pain is getting worse, she can’t. Then she lay

down. When she lay down, she think a lot about her pain and then she get worse". Hazel

Hazel's thoughts above were typical of many of the ladies and some of them showed some insights into what actions might worsen their pain such as focusing on it.

6. Shifting focus

Some ladies also showed insight into how shifting their focus away from thinking about their pain reduced their symptoms. They acknowledged that the group had helped them to do this, and for some this had led to them changing how they managed their pain.

"Before she was always laying down and thinking about her pain. And when she's thinking about her pain, she were getting more pain and... not able to control her pain. But now she's trying to control her pain and move more than before and do stuff for herself to just deal with the pain, and she's managing now". Kahmia

Attendance at the group was considered a welcome distraction from their thinking and remembering.

"She was feeling happy that she knows some of the ladies here and she meet the others too and it was very good for her to just ... she was forgetting her pain when she was ... while she was talking to the ladies and having a chat, conversation with them". Iris

And helped them focus on making friends and enjoying conversations.

"It was very good and very helpful for us to forget something and to spend one hour with friends and have relationship with the friend ladies and talk and ask questions. It was very nice". Hazel

7. Role of Medications

Ladies described issues with taking pain medication such as remembering to take their medication regularly. For example, Aster says: *"The problem is that she is forgetting the time that she has to take her medication, that's the only problem that she has.*

The interviews revealed some misunderstandings with medication, for example:

"She was saying that a couple of days ago she was trying to throw all her medication out, she was saying I can't take any medication anymore. And then her husband told her that if you don't take medication you will get very bad, you have to take medication to get well". Aster

The impact of changing medication had upon pain levels and group attendance was also discussed by ladies.

“Yeah, she was good for a couple of sessions, but then when she changed her medication, she get more pain and she couldn't cope her pain, and she couldn't attend the session. She said, “Even if I was attending the session, it's not going to help me because I have much pain”. Hazel

8. Making friends

The interviews provided some insights into the impact of the ladies' health upon integrating into life in Australia, their socialising and making friends. Despite all being part of the Yazidi refugee community living in a regional town, this was the first time many of them had met each other. Aster says:

“She didn't know any of them before, but she knows them when they come to the group. ... Because as soon as she come to Australia, she was sick, she couldn't attend TAFE to have friends there. So, she just know them here, the group”.

The ladies described their feelings of loneliness and isolation and how the group provided opportunities to meet people. For example, Iris says: *“[She] attend the group because [she] was lonely at home because [she] don't to see people. [She] want to meet people. [She] want to get something to ... better for [herself], to improve [herself] to forget [her] pain”.* For some ladies the group was the only opportunity they had for socialisation outside their home. For example, Kate asked Hazel: *“What else gets you out of the house?”* And Hazel responded: *“No”*, indicating that she had no other activities outside her home to attend.

The ladies' families had noticed the positive impact the group had on their wellbeing and how it provided a break, away from the house. They encouraged them to attend.

“She like talking and having communication with the other ladies and she was feeling good. Her husband was talking to her and she was saying, he was saying to her, go and spend one hour with the ladies because you are always at home. So you will feel better if you go out to have some friends outside and then talking to them”. Aster

Ladies appreciated the camaraderie the group offered. Hazel says: *“The good thing we put in a group woman together and having relationship, other friends, to know each other more, and, also, asking questions. Sometimes we've been laughing at each other and doing some questions like asking questions, and answering too, so it was very nice”.*

Bryony described how the group gave them opportunities to gain perspective because they were able to hear other people's stories: *“She is saying there is no one that wasn't having any problem – everyone has a problem – but each one has it different to each other, so everyone has a different story they were talking about, so it was good to listen to them and see their problems”.*

Finally, one participant Iris mentioned several times during her interview that she appreciated the way the group kept their discussions private.

“She said the group was very good. She’s happy with the group. She doesn’t have any concern about the group, and the way that she liked it, because they keep everything private in the group. Whatever they say, it will stay there”. Iris

None of the other ladies mentioned privacy. It was unclear to the researchers whether this was an unspoken agreement by the ladies, perhaps part of their culture, or something that they agreed during the group.

9. Expectations should be addressed prior to group attendance

Ladies attended the group with high expectations, some of which were met but some that weren’t. These are described below to provide the Wagga Red Cross with insights into the ladies’ expectations. It should be noted, although some of the ladies’ expectations were a little unrealistic, they should not be judged as unreasonable because they stem from a lack of knowledge about what is realistic to expect from a group and a misunderstanding of who and what the Wagga Red Cross is and does as an organisation. We appreciate the communication, memory, and cultural complexities that Wagga Red Cross must navigate when working with these ladies, but it is important to note that these expectations impacted how the group was received, and attendance at the group.

Some ladies’ expectations were met. These included: meeting people, making friends, getting out the house. For example, Laurel says: *“To find some information and to be out with friends sometimes”*. These expectations have already been discussed in the theme making friends. In addition, there was a perception that the group would involve opportunities to ask and answer questions. Aster says: *“It’s like she was expecting to like, you know, ask questions, answer questions and talk to each other”*.

The ladies described having high expectations of the impact attendance of the group might have upon their pain experience. For example, Dahlia says: *“I was expecting that I would get well”*. Some ladies had received physiotherapy treatment before in Australia and this impacted their expectations of the group because it was being run by a *Physiotherapist*.

Celsia: “They told me it was a physio so I thought that I would get something about physio, but it wasn’t”.

Kate: “Have you had physio over here?”

Celsia: “Yes. Four times. My GP was sending me to the physio”.

The above excerpts provide insights into the high expectations the ladies had for a group, including that they would become well from a short group intervention and that health professionals presenting at a group would be able to perform similar interventions to those that they might conduct individually.

Some reported that people thought they might get paid for attending and when they realised, they would not receive money, they stopped attending.

Aster: “She’s saying that they thought there was like money behind that group, like you know if they get in the group, they will get some money back for

themselves. That's why when they come two or three sessions and then they stopped coming".

Kate: "So there was a perception that they were going to be paid for doing the group?"

Aster: "Yeah".

Kate: "Why was there that perception?"

Aster: "Like most of them, they were thinking that they will get some money from the group. Like when they write their names, like in the group, they will get some money, like Centrelink. And this is beneficial, but when they come a couple of sessions and they didn't get anything, they said oh the group is not helping, it's not good for us, we don't want to attend any more".

Kate: "Do you get money for other groups?"

Aster: "No".

Despite not being paid to attend other groups, the expectation that money might be involved suggests a level of possible confusion about the role of Wagga Red Cross groups as well as an appeal for remuneration and emphasises the need to be explicit in what ladies will gain from groups. The example below provides further insights into the confusion and expectations some ladies had about the group and the role of the local Red Cross.

"So I told them also that if you want me to be comfortable or don't have mental health, I have my kids in Iran, in my country. You are the government office and help us to bring my kids. They are alone. They get a very difficult life there. This would help me to be better". Celsia

10. The group should be about more than pain

Ladies were keen to gain opportunities to practice their English language skills.

"To talk and discuss in English, to learn some English while talking". Hazel

Gaining English language practice opportunities was the most common suggestion from ladies when they were asked how the group could be improved. Celsia's answer below where she mentions 'another side of pain' underlines the ladies' holistic approach to their lives.

"The thing that [she] want to learn it was different, another side of the pain, like language, like if they teach [them] our language". Celsia

Kalmia's excerpt below provides further insights into why ladies were so focused into gaining further opportunities to practice their English and the impact that not speaking English had on their settlement and life in Australia.

"[She's] making relationship with people. If you don't understand the language, it's very hard, but if you know the language, it's going to be easier to have a discussion and make relationship with them." That's a problem". Kalmia

Ladies were also keen to hear more about living in Australia.

“She said if they talk to us about how the life is going in Australia, who government is, whether they have children and which way is good for the children to go with, which way’s not good, what they have to do for their life here, what they don’t have to do, what is good, what is bad for them, that stuff. They want more advice from Red Cross to just give them more information about how the life is going in Australia”. Iris

Don’t make it too simple

Bryony’s excerpt below shows how difficult it can be to pitch the education sessions at the right level for a group of women, who share a culture and refugee experiences, but nevertheless have diverse needs and who have different levels of insights and understandings of pain.

Kate: “So [Bryony], you were telling us that you had a suggestion as to how we could improve the group. Can you tell me about that?”

Bryony: “Yeah. She’s saying, like, I think the group was a little bit simple, she wants for it to be a little bit difficult, like, strong questions and lots of stuff to be very strong to them”.

Kate: “Can you give me an example of what you mean?”

Bryony: “Yeah. The example is, like, when we talk about the traffic light, like how the pain will start when they are getting a little bit pain and then it will increase and then will become a big pain. She said, we know, like, when you are in pain and if you don’t go to the doctor, you will get more pain. If you don’t control yourself or take any medication, you will end up with more pain”.

Kate: “You know that already, so you are wanting to go beyond that, is that what you are saying?”

Bryony: Yeah. We need to learn something that we don’t know”.

Bryony’s excerpt points to the importance of acknowledging that pain education should also include some active learning opportunities that challenge the ladies to put simple messages into action. For example, challenging pairs of ladies to develop their own scenarios to put the traffic light system into action and then getting them to present to group for feedback might be one way for them to develop greater insight into how difficult it can be to put simple messages like this into action and lead to a discussion of the barriers that can come up in life.

11. Group context

Some ladies found long periods of sitting hard and would benefit from sessions where there was greater opportunity for movement breaks.

"But for myself I didn't get any benefit from that because they're doing interview with us around one and a half hour but it was hard for me to sit for that whole time because I did a back operation before". Celsia

Ladies did not have tolerance for lots of noise, particularly other ladies talking loudly.

"So she said the ladies - so even the teacher was telling them "please stop talking and listen to us" and the others are like "look, my food, I did this food for my family" or these things so she's not comfortable with those things". Dahlia

Ladies didn't have a problem including other cultures in the group.

"Everyone is equal. She is happy if there is another lady from different culture. She said, "We're all human and we have to respect each other". Iris

However, different genders in the group drew a mixed response with some ladies happy for men to attend the group.

"It's okay even with us. We know the language". Celsia

And some showing a preference for a female only group.

"Yeah, only ladies is very good for us". Bryony

Qualitative Data from the Facilitators

Four overarching themes were identified from the analysis of the facilitators' focus group and *Physiotherapist's* interview:

1. Social aspects of the group
2. Learning
3. Making sense of pain
4. The impact of trauma.

1. Social Aspects

1.1. Social Connections: It's a place that's providing a social ground for them

The group provided important social opportunities for the participants to get to know other people in their communities. It was assumed that many of the participants who were invited to the project already knew each other as they have the same cultural background.

The ladies enjoyed getting out of the house and spending time with each other. Without the group some ladies may not have left the house. The women did not necessarily know each other before the group but were connected by shared previous experience which helped to create a bond amongst the ladies and potentially assist with social isolation. The ladies were able to focus on themselves and not have to think about the other external pressures of their lives. The group helped the ladies to feel as if they were not alone.

The social interaction with people from a shared background and understanding of previous experiences was a therapeutic aspect of the group and a potential reason the women enjoyed the group.

It's also a place that's providing a social ground for them. So they come to interact with each other, make friends

(F1)

The excerpt above suggests that the group was more than just a group to learn about pain, but it provided the opportunity to develop meaningful relationships.

A space for themselves: helping them to forget about their pain

The ladies didn't have many opportunities to focus on themselves.

Being able to be in that space and forgetting – most of them have commented like they forget a lot of the things that are happening outside. ... And just being there for that one hour helps them to forget about their pain or you know having a headache or you know it distracts them from the too many thoughts they have in their minds.

(F1)

The group allowed the participants a chance to focus on themselves and gave them permission to take time off from worrying about all the other things happening in their world. They were distracted from other things that were happening in their life.

1.2. Attendance: we don't know what's happened in their world

Facilitators noted that participants who attended enjoyed the group and were happy to participate in the sessions.

When people have attended I've found their engagement in the session and their participation in the session really good

(Physiotherapist)

They found that the ladies who attended the group had good levels of engagement but despite the potential social benefits from being together in a group, there was issues with attendance for the ladies. Many of the participants only turned up for some of the first group building sessions and then never turned up again, and some had an irregular attendance throughout. The Red Cross rang the ladies prior to each session to encourage attendance.

Some would say they would attend and then they wouldn't attend. So I guess even within 24 hours we don't know what's happened in their world that has resulted in them not being able to come

(F2)

It was not always clear why this happened but some of the reasons were explored below.

Not having a drivers licence:

For travel, these couple of ladies that they don't have travel licence so they have to have someone to drop them here and then take them back home too.

(F3)

Attending TAFE or other appointments:

The support workers would say is that they couldn't attend because, one, TAFE was a big one.

(F2)

Prioritising family, especially their children:

It's actually putting it into practice that is always a challenge and most of them they put family first, children and things like that.

(F1)

The above excerpts reinforce the importance of how the group is presented to the ladies. Perhaps if the structure of the group and the content of the group had been more explicit, more of the ladies would have maintained their attendance with the project. However, the low attendance may also reflect the various stages that the ladies were at in their learning, their pain experiences and readiness to make changes, and had the resources to attend the group.

In addition to issues with attendance, some ladies turned up late which meant that content had to be repeated or the sessions were reduced in duration due to starting late.

2. Learning

2.1. Group Formation- A Tangible Hook

Group formation was a key consideration during the planning of the project to ensure the group developed trust in each other and with the facilitators *before* the delivery of the pain content. To assist in building a strong group dynamic the plan was for the group to meet seven times before the pain content was delivered.

The group sessions were conducted on consecutive Mondays. The first session was in October 2020 with seven sessions before a planned break over the Christmas holiday period. The group then started back up again in January with the sessions that focused on pain.

Challenges arose with the planned group formation sessions. There were too many group formation sessions that did not include information on pain. The ladies wanted pain management strategies early in the project.

It was really challenging to have those weeks in the beginning, they were far too long for them because they seemed to really be keen on learning about pain and how they could support their pain or manage their pain.

F1

The facilitators identified that there was not a tangible hook for the ladies and that this was required to keep the ladies interested. Having a clear learning outcome or focus for each session would not preclude a focus on group formation and can be incorporated into the early sessions.

The other thing like we've mentioned before about bringing in a much more of a hook a lot earlier on. I guess we're kind of selling the project to people that this is what it'll help you with. So bringing that in as early as possible, even if it's not the pain sessions but delivering something really tangible, really early on. Like you can still do that while you're building the group and getting to know people.

F4

Facilitators found that when they did provide more structured sessions during the group formation period, such as sessions about sleep hygiene, these were received well by the ladies.

2.2. Development of teaching materials- “We don’t know, you tell us”

The nine target concepts from the pain revolution were used at the basis for the pain content ¹⁶. To make the group adaptable to the learners needs feedback was sought from the ladies as to the content they wanted included in the group. However, the participants were not sure what they needed or wanted to know.

The main response she said was “oh we don’t know, you tell us”.

(Physiotherapist)

The above excerpt highlights that it may be easier to provide feedback on a prototype plan of the intervention, rather than suggest ideas without examples. The ladies were not presented with the original plan of what was going to be presented so it was hard for them to provide meaningful

suggestions. There was a sense that they may have come into the group with the expectation that “experts” or “doctors” were going to tell them what was wrong and what they needed to do.

2.3. A cultural Lens: “Make it as relevant and culturally sensitive as possible”

A working relationship was established between the *Physiotherapist* and group facilitators that allowed cultural checking of the planned material and suggestions to be made on how material could be presented to make it culturally meaningful and culturally safe. The target concepts were tailored by introducing aspects of Yazidi culture to create a more meaningful connection to the content. This cultural connection potentially created more powerful learning opportunities and made the concepts more approachable.

Doing a bit of research prior into Yazidi culture and then being able to have the knowledge exchange with [names of Facilitators] in particular but all of the facilitators because [name of F2] knew the group prior to that session. And to be able to run some of the concepts or adapted concepts from the pain science by these guys first to see what they thought would work and not work. And working with [names of facilitators] each week in terms of trying to send out what material I'd use and a rough transcript so that we could check translation would be okay. Just to try and tick as many boxes as possible to again make it as relevant and culturally sensitive as possible.

(Physiotherapist)

In the above excerpt, the *Physiotherapist* described the measures she took to ensure that the material she presented was as culturally relevant as possible. She also sent her proposed script to the translators before the session to give them time to view the pain education material before they had to translate it.

2.4. Location of Sessions: “A safe space”

The sessions took place in a room located at the Red Cross that was set up in a similar way to a classroom. The chairs and tables were arranged in a horseshow configuration with a projector at the front of the room. The *Physiotherapist* was initially concerned whether the classroom-like environment was appropriate or if other options should have been considered such as outside in a park.

I think initially I was thinking ...should we stay in a class, like have it like a classroom if they're not really used to that environment. Or should we even be... walking across to the lagoon and walk and talk.... I did get some feedback from [names of facilitators] that the room had become quite a safe and comfortable space, they were used to meeting there, it was familiar.

Physiotherapist

The facilitators considered that it was important to simplify this aspect of the sessions by keeping the location of the sessions the same.

2.5. Language barriers: keep the language quite simple and chunk it down

There was a mix of proficiency amongst the ladies in understanding and communicating in written and verbal English. None the of the ladies were fluent English speakers and most of them had

limited ability to comprehend or communicate in English. The *Physiotherapist* considered the low level of English in planning and delivering the sessions. She used a variety of communication strategies to help communicate the content.

She presented nonabstract visual images to illustrate a concept:

I did go with some PowerPoint but primarily pictures that even weren't too abstract, to make things quite clear that this is the picture and then tell the story

(Physiotherapist)

She kept the messages short to aid understanding and interpreting:

I tried to keep the language quite simple and chunk it down. So even for myself I'd break it down into small paragraphs knowing that [name of facilitator] also had to take that on board and then interpret it.

(Physiotherapist)

She chose simple language to explain the pain concepts:

"...we can't sort of ask "how do you conceptualise pain". Or they might not even understand you know "what do you think pain is telling you".

(Physiotherapist)

Finally, she kept the education sessions short:

I really planned that for me what I was going to say, could be no longer than about 15 minutes because if it then took 15 minutes for [name of interpreter] to ... interpret it and we're getting information coming back and forward. And maybe time for questions at the end or allowing for participants to be late within that hour, hour and a half time frame.

(Physiotherapist)

It is worth acknowledging that although these strategies sound simple, they would take considerable planning and consideration to implement. The *Physiotherapist* had to consider what it would be like to hear these concepts from a completely different frame of reference. Thus, implementation of the strategies was complex and required an effective working relationship with the translators and members of the target cultural community.

2.6. Reflection Sessions: That was really helpful

Despite the efforts and consideration for delivering the content in a way that was easy to understand it was identified that poor memory of the ladies affected retention of information.

Memory, concentration those sorts of things were an issue for each of them.

(Physiotherapist)

The ladies had challenges with their memory and concentration which impacted their ability to retain information between sessions. The Pain Revolution target concepts required participants to understand abstract themes and ideas and retain this information to link ideas together between sessions. It was reported that the ladies struggled with their ability to retain information and to be able to remember content from previous sessions. It is not clear if this was due to generally not

being able to remember or that they did not understand the concepts that were discussed so therefore, they would not have been able to recall and discuss them.

The pain education sessions were interspersed with reflection sessions which were run by Red Cross facilitators.

I feel like that was really important to have because ... sometimes they forget or sometimes it's just they want to discuss more or they want to have more information or just what did this mean or even [Physiotherapist] giving some homework, that was really helpful to be able to come back the following week.

F1

Thus, the reflection sessions were a useful approach which helped the ladies recall what had taken place in the pain education session the week before and keep the momentum going between sessions.

Interactive Activities: “we had the best engagement”

The best engagement from the ladies came when they took part in a learning activity that had an interactive and engaging component and involved sharing thoughts and beliefs that had been designed to be culturally appropriate. This activity is described from the ladies perspective under the theme of peacocks and lions on page 20.

Where they did do an interactive activity was probably where we had the best engagement.

(Physiotherapist)

However, it is not clear if the ladies were able to translate the activities into knowledge and behaviour change.

As noted above attendance at the sessions was low and not all participants attended all sessions. While it was reported that the ladies struggled with memory and concentration, they were keen to learn as much as possible. This meant that the reflection sessions were very important for being able to jog the ladies' memories and help them consolidate key messages.

2.7. Experiential Learning for active strategies: “letting them touch and feel or experience”

Experiential learning is distinct from interactive activities. Experiential learning describes active engagement in a strategy so that the participant learns by their experience, whereas interactive activities relate more to understanding a particular concept. Both are essential to a project about living with pain.

The *Physiotherapist* reflected upon the need for greater experiential learning in subsequent groups because she had observed the positive impact that active strategies had upon participants learning and recall of concepts.

I think the big thing on my radar ... is maybe bringing in a bit more of the experiential learning and then referring back to that with the education. So letting them touch and feel or experience a little bit more during the course of the project.

(Physiotherapist)

The *Physiotherapist* explained that in future projects she would be keen to introduce experiential learning experiences earlier and suggested that combining experiential learning with information about why you use active strategies might be a useful progression. In the focus group, the facilitators agreed with the *Physiotherapist*'s proposal and suggested that increased experiential learning would also provide greater opportunities for the ladies to engage in community activities.

So like the idea of a walking group like you just said. But going for a walk and then really tangibly suggesting other people can do that at ten o'clock on a Thursday. And do this if you would like to go. So you don't have to be there but really firmly planting those seeds. And I think you know having a yoga session but having it with someone who already runs ones in the community that's affordable or free. And then trying to set it up so people can actually go. So focussing on really achievable things in terms of other connections into the community.

(F4)

3. Making sense of pain

As noted above, the ladies were keen to learn about pain and to develop strategies to assist in reducing their pain. The pain education content was based on nine target concepts from the Pain Revolution¹⁶. The target concepts were developed by pain researchers and clinicians from a western culture. One of the key goals of pain education is to help people make sense of why there are experiencing pain and then to develop strategies based on that understanding to assist in the management of their pain.

3.1. Making sense of their Pain: not as tainted by a bio-medical model

The *Physiotherapist* and the facilitators agreed that the ladies were insightful when it came to trying to make sense of their pain.

I think again a lot of the pain science is directed at Western cultural beliefs and misconceptions about pain. But I found the group really insightful, and I guess the way I would say it is not as tainted by a bio-medical model as potentially what Western culture is.

(*Physiotherapist*)

As you can see from the above excerpt, the ladies understanding of pain experience was influenced by their culture and the ladies were found had greater insight into the mind-body connection than their typical clients who were mostly from a western paradigm to health.

They were quite insightful about how particularly their thoughts, feelings and past experiences impacted on pain. And I think they also certainly had an idea about how what we do and the people we're with can influence pain. They already had some strategies that they're using in relation to those things.

(*Physiotherapist*)

The above excerpt suggests that the *Physiotherapist* found that the ladies already appreciated how their thoughts, feelings and how their past experiences shaped their pain experiences. The *Physiotherapist*'s insights underline the importance of understanding the health culture and worldview of a population to ensure that pain science messages are adapted and relevant to the specific population to have the chance to effect meaningful behavioural change.

3.2. Behaviour Change and Management Strategies: *did it change once they left the room*

There were multiple challenges in achieving meaningful change in this cohort. Many of the ladies had little understanding of English and had experienced trauma. The sessions were conducted through a translator and no clear schedule had been submitted to the group so they weren't sure what they would gain from the sessions. Attendance, perhaps because of some of the above, was low.

Even without these obstacles, a challenge for any pain group is how pain education and knowledge of pain is translated into behaviour change to support potential successful management approaches. Within the group it was not clear if participants knowledge and beliefs changed. And without a change in knowledge and beliefs it is difficult to change behaviour.

Facilitators felt that for the ladies that consistently attended the sessions, they understood the content in the sessions which were reinforced through the refresher sessions.

I'm thinking there in terms of that behaviour change, did it change once they left the room, I'm not sure. Because there wasn't, you know, are they thinking about it, I don't know. So that's probably one of my unanswered, you know, how has it helped in that way. But their responses in the session were appropriate and, you know, to what we were talking about. And they had good examples from their experience.

(Physiotherapist)

The evidence from the *Physiotherapist* suggests it was not clear if the knowledge and understanding of pain from the group project resulted in meaningful behaviour change that in turn, would increase function and decrease pain. This is an area for potential research in the future.

4. The Impact of Trauma

4.1. Past traumatic experiences: *It came up every session*

The past traumatic experiences of the ladies were a big focus for them and linked to their pain experiences.

It came up every session and actually, mostly it was initiated by the participants, mainly in response to some of the concepts again. I might have mentioned not trauma specifically, but our past experiences and things we've learned or those sorts of things can be influential and then someone might comment.

(Physiotherapist)

The excerpt above, highlighted that trauma was a common topic in their discussions but was not always a planned part of the discussion. The *Physiotherapist* described how she integrated the ladies repeated referrals to trauma into the discussions about pain but did not address their individual experiences directly. She identified two factors that impacted the group's discussion about trauma: her nervousness and the group's rules.

But I think it was important that we addressed the link and that was certainly in my curriculum. But I was quite cognisant, and I was probably a little bit nervous as to how that was going to go. But I think, again, because the group rules were set, we negotiated that quite well.

(Physiotherapist)

Facilitators found there were differences in how the women wanted to discuss past traumatic experiences and its impact on their pain. Some women were very keen and willing to discuss their previous trauma. Other ladies were upset at the idea of hearing other people's previous experiences of trauma and did not want to discuss their past trauma. As a result of these differences in approaches, the group set up ground rules and it was decided that previous trauma and general references to their backgrounds would not be discussed. However, these were agreed at the very beginning of the project, before the pain education sessions, and not re-visited again. The *Physiotherapist* noted that this potentially limited discussions about the impact of trauma.

Referenced trauma and past experiences but they didn't go into specific details of their own.

(Physiotherapist)

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Appendix 1: Facilitator Focus Group Guide

Introduction

Researcher introduction - Thank you for your interest in our research, which is about your experiences of facilitating the Living with Pain Group.

Reinforce why we are doing it- to improve future programs etc.

Review consent to participate – Do you have any questions about the research or your participation?

You are free to say as much or as little as you want. If there are questions you don't want to answer just let us know. The focus group will take about one hour but if you need to take a break please let us know. You are free to stop and withdraw from the focus group at any time without any consequences or any questions asked.

If there is anything you do not feel comfortable sharing with the rest of the group you will have the opportunity to provide additional feedback after the focus group.

Do I have your consent to proceed with the discussion?

Do I have your consent to audio-record this discussion?

A few rules before we begin:

- Everyone gets a chance to speak and has a right to express their opinion.
- It is not a test.
- There are no right or wrong answers.
- It is not expected that everyone must agree on all points of discussion.
- It is not expected that everyone will have had the same experiences.
- Please let someone finish what they have to say, before giving your perspective on the discussion.

The session will be facilitated by both Ian & Kate.

Focus Group

General Themes and Questions of Focus Group

1. Overall, would anyone like to provide their overall impression of the project?
2. Were there any expected/unexpected outcomes?
3. What were the challenges for the participants in attending the project?
4. What do you think were the benefits for the participants in attending the project?
 - a. If needed prompt on social benefits and specific benefits to the information provided/ pain

5. The initial aim for the group was to:

“Develop a group for clients that experience chronic pain and to provide a suitable platform for them to receive information and support on ways to manage their pain.

In addition, it was hoped that by attending the group the people would improve their knowledge and awareness on how to assist themselves with managing their pain. “

Reflecting back on the initial aims for the group do you think the aims were met?

- a. What worked well in the group to achieve the aims
 - b. What do you think would need to be changed in future groups to achieve the aims?
6. Thinking broadly about the content of the sessions that has been delivered to date- what has worked well (and why) and what do you think could be changed in future programs (and why)?
 7. Thinking about the overall design of the project what worked well and why and what do you think could be changed in future programs and why?
 - a. The frequency of the sessions- every week
 - b. The duration of the sessions
 - c. What could be done to ensure high levels of attendance.
 8. Thinking specifically about the sessions before Christmas – was this part of the project successful?

- a. Why?
 - b. What did the participants gain from taking part in this aspect of the project?
 - c. Is there anything you would like to change about this aspect of the project?
9. Thinking about the pain education sessions – what worked well (and why) and what do you think could be changed in future groups (and why)?
- a. What did the participants gain from taking part in this aspect of the project?
 - b. Is there anything you would like to change about this aspect of the project?
10. Thinking about the reflective sessions between the pain education sessions – was this part of the project successful?
- a. Why?
 - b. What did the participants gain from taking part in this aspect of the project?
 - c. Is there anything you would like to change about this aspect of the project?
11. (If needed) Thinking specifically about the content that was provided as part of the pain education sessions and the way in which the content was provided. Do you think this should be changed for future groups?
- a. Why?
 - b. How?
12. Is there anything else you would like us to know to help us evaluate the group?
13. Before we talk about the project itself, can you tell me what you, personally, have learnt about pain from facilitating the project including Kylie's pain education sessions?

Appendix 2: Ladies Interviews Guide

INTRODUCTION

- Introduce self – researcher at TR/CSU – physio like Kylie
- We have been asked to evaluate the Living with Pain group and would welcome your thoughts
- I would like to talk to you individually with Jilan translating. I will ask you a few questions about what you liked about the group and what you learnt in the group. I'm keen to hear how the group has impacted your pain experience and hear what you think should be included or removed from the group. If there were any questions you do not want to answer, you can let me know and we'll can move on to the next one.
- I would record these chats so that we can then analyse them and summarise everyone's feedback into a report. We will use quotes from un-named participants in the report, but no-one will know what you have said, unless you tell them, because we will not identify any participants who take part.
- To acknowledge your time and thoughts on this we will give you a \$50 voucher for supermarkets after the interview.
- We would also like permission to look at your responses to the surveys that Red Cross have undertaken. This would allow us to analyse the groups responses and provide further feedback to the Red Cross.
- I'm happy to answer any questions about the research either today or next week.
- Please take one of these information sheets about the research and have a think whether you wish to take part or not.

Interview Guide

Overview (experience)

- 1. Why did you come to the group?**
- 2. What were you expecting from the group?**
- 3. Tell me what it's been like joining in the group?**
 - a. How did the group make you feel?
 - b. How would you feel if there were other cultures/genders in the group?
 - c. What did you think about the size of the group? (content analysis (CA))
 - d. What did you think about the way the group was managed?
How did that impact your experience?

- 4. Were there any challenges in attending the group?**

- 5. Thinking about the sessions before Christmas – what did you like about them? What did you not like about them?**
 - a. What were you hoping to get out of the sessions? CA
 - b. What advice would you offer the Red Cross in the future about the sessions before Christmas.

- 6. Thinking about Kylie's pain sessions – tell me about your experience with the sessions.**
 - a. What were you hoping to get out of the sessions? CA?
 - b. What advice would you offer the Red Cross in the future about the sessions before Christmas.
 - c. What did you like about them?
 - d. What did you not like about them?
 - e. What advice would you offer the Red Cross in the future about the sessions before Christmas.

- Thinking about the reflection sessions between Kylie's sessions – how did you find these sessions?**

- 7. What did you learn about pain?**
 - a. What did you learn about managing your pain?
 - b. What did you think about the way the information about pain was presented/
delivered

- c. How do you feel/think about your pain now?
- d. Is there anything else that you would like to know about pain or managing your pain? CA
- e. Do you think you will manage your pain differently since taking part in the group?
Please explain your answer.

Appendix 3: Physiotherapist Interview Guide

Introduction

Researcher introduction - Thank you for your interest in our research, which is about your experiences of developing and delivering the pain science component of the Living with Pain Group.

Review consent to participate – Do you have any questions about the research or your participation?

You are free to say as much or as little as you want. If there are questions you don't want to answer just let us know. The interview will take about one hour but if you need to take a break please let me know. You are free to stop and withdraw from the interview at any time without any consequences or any questions asked.

Do I have your consent to proceed with the discussion?

Do I have your consent to audio-record this discussion?

A few rules before we begin:

- It is not a test.
- There are no right or wrong answers.

Interview Guide

1. Did you feel prepared going into the project?
2. Is there anything in hindsight that you wish you knew going into it that may have helped about the population particularly, about the people that you were engaging with?
3. What did you feel worked well with regards to delivering the content
4. Reflecting on the changes you made to the project, was it successful and would you do it differently?
5. Thinking about the reflective sessions between the pain education sessions – was this part of the project successful?
 - a. Why?
 - b. What did the participants gain from taking part in this aspect of the project?
 - c. Is there anything you would like to change about this aspect of the project?
6. Thinking specifically about the content that was provided as part of the pain education sessions and the way in which the content was provided. Do you think this should be changed for future groups?
 - a. Why?
 - b. How?
7. Thinking about the pain education sessions – what worked well (and why) and what do you think could be changed in future groups (and why)?
 - a. What did the participants gain from taking part in this aspect of the project?
 - b. Is there anything you would like to change about this aspect of the project?
8. How was it working with an interpreter?