2013

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Citation/Publisher Attribution

Gillsjö C, Schwartz-Barcott D, Bergh I (2013) Learning to Endure Long-Term Musculoskeletal Pain in Daily Life at Home: A Qualitative Interview Study of the Older Adult's Experience. J Gerontol Geriat Res 2:136. doi:10.4172/2167-7182.1000136
Available at: http://dx.doi.org/10.4172/2167-7182.1000136

Gillsjö et al., J Gerontol Geriat Res 2013, 2:4
http://dx.doi.org/10.4172/2167-7182.1000136

Gerontology & Geriatric Research

Research Article Open Access

Learning to Endure Long-Term Musculoskeletal Pain in Daily Life at Home: A Qualitative Interview Study of the Older Adult's Experience

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Abstract

Background: Worldwide, there is an increasing number of older adults, the majority of whom remain living at home. Not infrequently they live with long-term pain, especially musculoskeletal pain, which is associated with increased disability (physical, psychological, social) and a negative impact on quality of life. A deeper understanding of how older adults experience living with this type of pain is needed in order to improve well-being and quality of life. The study focused on the actual experience by living with this global, prevailing and disabling type of pain. The aim was to describe commonalities in how older adults endure long-term musculoskeletal pain in their daily life at home.

Methods: This inductive, descriptive study included qualitative semi-structured face-to-face interviews with 19 participants (66 to 88 years) in their homes. Qualitative content analysis by Graneheim and Lundman was used to identify themes crossing participants' experiences of enduring long-term pain in their daily life. Interviews were audio-recorded and transcribed verbatim.

Results: All participants felt forced into "learning to live with pain" (main theme), in order to endure their pain. In time, they learned that: taking the pain as it comes, one day at a time; balancing the pain with activity, thoughts and emotions; self-talking; trying to be less of a burden to family and others; and capturing, enjoying and valuing moments of pleasure (sub-themes) helped them endure the pain.

Conclusions: This experience was dominated by learning. The approaches generated to learn to endure pain in daily living by these participants should be discussed with older adults in similar situations for further additions, refinements and validation. Nurses can help to ease the older adult's suffering by tailoring individualized and holistic care focused on guiding the older adult in learning to live with pain and preserving and promoting health and well-being with a maximum of care and a minimum of intrusion.

Keywords: Older adults; Long-term pain; Musculoskeletal pain; Home; Nursing; Home health care; Qualitative content analysis

Introduction

Musculoskeletal pain is the most common long-term pain for older adults living in their homes [1-3]. There is an increase worldwide in musculoskeletal conditions accompanied with this type of pain. The pervasiveness and global nature of this problem led the World Health Organization (WHO) to declare 2000-2010, "The Bone and Joint Decade" in an effort to raise awareness and understanding of its significance for the individual, health care system and society at large [4,5].

There is an extensive literature about long-term musculoskeletal pain as a major health problem among older adults [1-3,6-14]. The prevalence of this type of pain tends to increase with increasing age [3,15]. Musculoskeletal pain is associated with lower level of physical activity [16], increased risk of disabilities in daily living [6,17-23] including sleeping difficulties [24], increasing risk of falls [25,26], depressive symptoms [27,28] and impaired quality of life in relation to health and well-being [28-31].

To-date researchers have focused primarily on the prevalence and nature of the pain, its treatment and impact rather than on how community dwelling older adults actually experience living with the pain at home. How do older adults endure long term musculoskeletal pain that have lasted at least for 6 months in their daily life at home? This question needs to be addressed in order to help health care providers tailor individualized care to preserve and promote health and well-being in this population.

Background

Qualitative studies that focus on how older adults (65 and older) actually live with musculoskeletal pain at home are highly limited. Most studies have been quantitative and the focus has been mainly on older adults in assisted living facilities, although a few have included community dwelling older adults. Recently a small group of researchers have begun to use qualitative research methods to explore the perceptions and experiences of community dwelling older adults living with long-term pain. Sofaer et al. [32] interviewed 63 older adults living in their homes or assisted living facilities about the limitations they faced because of long-term pain and the strategies they used to deal with them. These older adults strived for independence and control and tried to adapt to a life with pain. They used aids and adaptations to the home and garden to help maintain their independence and they spoke of "pacing oneself, helping other people," prayer and "looking good and feeling good" in trying to adapt. Seomun et al. [33] interviewed 16 older adults in their home as part of a concept analysis of coping with long term pain while living with arthritis. They identified five coping strategies, including tuning (controlling the body movement until the pain goes away), attention diversion, exercise, medical regime

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Received August 23, 2013; **Accepted** October 19, 2013; **Published** October 21, 2013

Citation: Gillsjö C, Schwartz-Barcott D, Bergh I (2013) Learning to Endure Long-Term Musculoskeletal Pain in Daily Life at Home: A Qualitative Interview Study of the Older Adult's Experience. J Gerontol Geriat Res 2: 136. doi:10.4172/2167-7182.1000136

and giving up control. Blomqvist and Edberg [34] interviewed 90 older adults about their experience of living with long term pain at home or in a sheltered accommodation and dependent on home health care providers in daily life. Some of the older adults expressed satisfaction in their situation in spite of pain and viewed themselves, their pain and significant others positively whereas others expressed dissatisfaction with a negative connotation in life. The authors concluded that health care providers need to be sensitive to and acknowledge the individual's experience of pain in the specific situation. The need for additional research has been argued by Helme and Gibson [35]. They have argued the need to more deeply and more fully understand the problems caused by pain in the older adult's life. They highlighted the difficulty in obtaining in depth data of this experience with the commonly used designs and questionnaire format. Furthermore, Miaskowski [36] and Gartrell [37] have stated that researchers need to be attentive to how older adults experience pain and the distress and disabilities in life related to this health problem. Cleary, one can assume that there is a need to conduct further research aimed at clarifying and gaining an in-depth understanding of the older adults' experiences of living with long-term musculoskeletal pain.

In response and in an effort to expand this body off work, the authors designed a study to address the older adult's experience of living with long-term musculoskeletal pain at home. Face-to-face interviews were completed with 19 community dwelling older adults living with long-term musculoskeletal pain in their home. The overall aim was to obtain a more in-depth understanding of older adults' experiences of living with long-term musculoskeletal pain at home. The goal was to capture this experience as fully as possible in regard to both variations and commonalities. An initial phenomenographic analysis was completed in order to describe the different ways in which older adults deal with daily life while living with long-term musculoskeletal pain at home. The result of this analysis has been published [38]. The wide ranging categories ignore, struggle, adjust and resign reflected the distinctly different ways the older adults' dealt with daily life at home while living with this type of pain.

Despite these extreme variations, it became obvious during the initial analysis of the data that there were commonalities in the older adults' experiences of living with this type of pain. Daily life for all the adults was an act of endurance and there were important commonalities in how they endured the pain. The penetrating sense of endurance throughout the data motivated the following analysis, one that focused on the commonalities in the older adults' experiences. Based on the studies reviewed and the conducted analysis the aim of this analysis was to describe commonalities in how older adults endure long-term musculoskeletal pain in their daily life at home.

Methods

Qualitative face to face interviews were chosen to collect data since it gave an opportunity to obtain a description of the participants' experiences in a situation where the researcher momentarily could obtain confirmation of the participants' verbal and non-verbal expressions [39,40]. Graneheim and Lundman's [41] approach to qualitative content analysis was chosen to identify commonalities in how 19 older adults endured the pain in their daily life at home. Content analysis as a research method was developed originally as a quantitative research method in several disciplines during the 20th century. More recently a qualitative type of content analysis was added [42]. Graneheim and Lundman [41] developed a qualitative style of content analysis that is interpretive in nature and used to describe or illuminate a phenomenon by identifying both the manifest (the obvious) and latent (underlying meaning) content in a text. This approach remains close to the languages used by participants, rather than the more traditional, realist approach which focuses on single words and phrases [43].

Participants

The inclusion criteria for this study were community dwelling older adults aged 65 or above, who for at least the past six months, had lived with long-term (persistent or regularly recurring) musculoskeletal pain at home and had received home health care services. In addition they had to be willing to participate in the study and be able to understand and answer questions. The older adults who met the inclusion criteria were identified by the home health care providers in their community. They were given an informational letter about the study and asked if they would be willing to be contacted by the first author. Each potential participant was contacted by the first author by phone to answer any questions and to give more detailed information. Additional written information and a letter for informed consent were sent to those older adults who were interested and a time was set up for an interview in the older adult's home for those who decided to participate in the study.

A sample of 19 older adults, 18 women and one man, aged 66 to 88 years, (mean 79 years), from three different communities in Sweden participated in the study. Five were married, 12 widowed and two were divorced. The older adults had lived with long-term musculoskeletal pain ranging from two to 50 years and one woman had lived with this type of pain for about 75 years, almost her entire lifetime.

Data Collection

Semi-structured, face to face interviews were conducted and carried out as a conversation by the first author in the year of 2006. This researcher is an experienced registered nurse with a post graduate diploma as a public health specialist in nursing, and family nurse practitioner with a master of science in nursing and doctoral prepared in qualitative research method. The researcher had no personal relation with the participants. An interview guide was used to frame the conversation while also allowing the dialogue to develop in relation to the participant's responses. The interview, conveyed as a conversation allowed the older adults to reflect upon and articulate their experiences in their situation and to choose what content to share with the researcher. The interview guide consisted of open ended questions with subsequent follow up questions used to explore and describe how each participant lived with long-term musculoskeletal pain in their daily life. More specifically, it consisted of a series of questions covering older adults general description of their pain, how they lived with it in daily life, its influence on their daily lives, how they dealt with daily life while living with this type of pain, contacts and support from health care providers and significant others and their thoughts about the future. Interviews lasted from 35 to 115 minutes. They were audio-recorded and transcribed verbatim.

Data Analysis

There were six major steps in the analysis. First the transcripts of all the interviews were read by the first author to become familiar with the text and to reflect upon the content. The second reading was done to confirm the aspect of *enduring long-term musculoskeletal pain in daily life at home* which constituted the foundation for the research question: *What are the commonalities in how older adults endure long-term musculoskeletal pain in their daily life at home?* The notion of enduring while living with pain was reflected upon throughout the whole text, both implicitly and explicitly as the focal point in the older adult's

situation. Thirdly, each interview was read and re-read to identify the content relevant to the research question. As a fourth step, meaning units consisting of words, sentences or paragraphs related to the aim were identified in the interviews. The meaning units constituted the foundation for condensation and abstraction into codes conducted separately for each interview. In the fifth step, the meaning units were condensed and the essential contents in the condensed meaning units were abstracted and labeled with a code. One example of text that constituted a meaning unit answering the research question was *"... there is no one that can do anything…I have to continue and have this pain as I have…one learns, that's the only word I can say, that one has to learn…"* This meaning unit was condensed to *"Realizes that no one can help her with the pain and that there is nothing else to do other than to learn to live with the pain"* and further abstracted to the codes *Learn to live with pain, Tries to control her situation* and *Bear the pain alone.*

In the sixth step, the codes were compared for similarities and differences in content and sorted into five preliminary themes: learning to endure and get through the day; controlling oneself and daily life; self talk; not be a burden; meaning and pleasure in life that had emerged during the analysis. Each code, explicitly (manifest content) or implicitly (latent content), reflected the theme it was sorted into. The codes in the preliminary theme: *learning to endure* and get through the day reflected the learning with a day by day focus. The codes: *"learn to live with pain to endure", "take the unpredictable pain as it come"* and *"take it day by day"* were explicit codes (manifest content). Others as *"keep habits and routines", "tries to live life despite pain, tries to endure"* were codes that reflected the theme more implicitly (latent content). During the analysis the component learning to endure pain, in one of the preliminary themes was interpreted as an underlying thread across all the five preliminary themes. Based on this interpretation, *learning to live with pain* was labeled as the main theme under which the remaining five preliminary themes were subsumed. The older adults' experiences in their situation can be viewed in light of the main theme which in combination with the sub-themes, as being the parts, constitutes the coherent whole of how older adults endure long-term musculoskeletal pain in their daily lives at home. The first and second author, an experienced professor and researcher on the topic of pain in hospital and home settings and an expert in qualitative methods, analyzed the first interview separately, compared, discussed and reached consensus about codes and potential themes. The first author continued to analyze the following interviews and each analysis (condensations, codes and preliminary themes) were discussed. There was close communication between the first and second author in the phase of labeling codes, sorting them into preliminary themes and naming final themes. The analysis was an iterative process back and forth across the steps and not in a linear process as might be understood from the description above.

Ethical Considerations

The study was approved by the Ethics Committee at the University of Gothenburg, (034-06). In addition, approvals were given by the heads of the social welfare and home health care services in the communities of concern for the study. Furthermore, the older adults consented to participate in the study both verbally and in writing. Several reminders were given prior to the interview that participation in the study was voluntary. The data were treated as confidential to protect each participant's identity.

Results

The community dwelling older adults in this study felt that they were forced to endure pain in their daily lives at home. They felt that their pain could not be eliminated, controlled nor managed. Instead, the question was how to endure living with it? In the interviews many of the older adults referred explicitly, others implicitly that they had to learn to live with the pain. Thus learning to live with pain became the main theme. The five sub-themes reflected how these adults had learned to endure pain in their daily life, continue with daily activities and find meaning in life. These included:

- taking the pain as it comes, one day at a time;
- balancing the pain with activity, thoughts and emotions;
- self talking;
- trying to be less of a burden to family and others;
- capturing, enjoying and valuing moments of pleasure

Main and sub-themes are described below and illuminated with quotes from the interviews. The quotes collectively stem from 10 interviews. These were the most illustrious. However, every interview was reread to make sure that the illustrious quote was synonymous with the text in the interviews.

Learning to Live with Pain

For the older adults in this study, the pain was continuously ongoing and no one expressed any belief in the possibility that it could be eliminated or controlled. They had come to believe that they just had to learn how to endure.

It varies, one just has to go along with how the body reacts because it just comes, and one can't decide about that oneself, the pain comes… when it comes…I said at the hospital; could you give me something that could make me almost well?...They say; 'you have to be happy for what we do for you. We help you as much as we can'….I have no more wish, not for me at least, one just has to endure.

The older adults could not recall ever having been taught how to endure. They spoke of varying degrees of support from health care providers in their homes, although still more often alone with their pain. They felt that they had to endure primarily on their own. Not infrequently, health care providers seemed to unwittingly reinforce the idea of having to deal with it on one's own. Below is one woman's description of a conversation she had with one of her physicians.

… it is so violently painful that I don't think I can endure it, I can't handle this. 'Yes, but you will' said the doctor 'because you are so mentally strong, you will be able to manage this'.

Several of the older adults brought up the need for additional, individually tailored advice and support from health care providers both now and in the future.

Earlier I had one doctor for many years and that felt so good, we knew each other….one needs someone that, so to speak, someone that pays a little attention….One wishes that…there was a pain unit that one, at least could consult....to at least hear if there could be anything available to try….it's always good to hear a little…but it's not available so it's no use thinking about it.

In summary the older adults in this study were pretty much on their own when trying to figure out how to learn to endure living with long-term musculoskeletal pain in daily life. There was no learner's guide, even though others told them that they could endure. In this continual process of learning, they drew from what they had learned in life while at the same time being open to new aspects that could help. There was this underlying expectation that pervaded in the older

adults' lives about pulling themselves together and figuring out on their own. This expectation was established within themselves, but was also felt to be present among family, friends and health care providers. They did their best to guide and coach themselves in the effort to meet this expectation. Each older adult had some kind of support but the extent and content of it varied individually in relation to the current situation. The older adults felt that they had to learn how to endure on their own despite the fact that they had people around them at different point of times during a day. They had various support from health care providers regarding their medication but none were fully satisfied with the relief of their pain. They just tried their best to adjust their medication in relation to their pain.

Taking the Pain as it Comes, One Day at a Time

The older adults in this study had learned that to take the pain as it came and get through the day, one day at a time, helped them endure the pain and continue with their daily lives. Many of them declared that they were old now and circumstances like pain were a part of aging. One women declared *"I get older and older so I don't have much time left, I can die any day…one hangs on, day by day, that's how it is and one has to take one day at a time, one has to live…I live with this pain, one has this pain in the body."* The unending pain had become a natural part of daily life. Some even came to view the pain as a friend in life. One women said *"…it aches all the time. One finally becomes, so to speak friends with the pain when it's aching, aching and aching always, always, always"*. The older adults had become used to the presence of pain with all its differing levels of frequency and intensity and locations that could not be predicted on any given day. One woman said:

One lives with the pain, one certainly does. Sometimes one feels better and sometimes one feels worse….there is nothing one can do about it....now one has that crap so it's nothing else to do but to live with it…. one has to take it day by day.

The older adults lived with daily pain which caused various degrees of difficulty in their effort to continue their daily lives. They felt that they had no other choice in their situation then to learn to endure and incorporate the unpredictable pain into their lives. They had concluded that the only way to be able to endure was to learn to live with their pain. One component in the learning to live with pain was to take the pain as it comes, one day at a time to get through each day for the rest of their lives.

Balancing the Pain with Activities, Thoughts and Emotions

The learning to live with pain in daily life was a continuous ongoing balancing act where the older adults tried their best to balance their pain with activities, thoughts and emotions in order to endure the pain. Balancing daily life was a matter of learning through the use of trial and error, with varying levels of success.

Clearly, there comes certain times when you do things and it doesn't work but one is so, it's so routine that one tolerates it anyhow….one becomes both morose and willful sometimes but it pays off poorly when one is alone…there are many times when one has to rethink and do something else instead.

Movements of the body were painful for the older adults but they wanted to maintain their ability to move about. They tried their best to balance their movements and positioning of their body to make the pain as tolerable as possible in the effort to find a good position or move about as intended.

I go where I'm heading….if I for example want to go to the bathroom and sit on the toilet I would need to do this very, very carefully…sit down very carefully because if I sit down sloppily or too fast then it hurts terribly, to the point that it makes me scream.

Furthermore, holding on to habits and routines helped the older adults stay as active as they desired and endure the pain. One woman described her day from the morning when she got up until bedtime. *"That's how my day works…and then I start the next day with the same routines, so goes my day….if I would lie in bed and sense how bad the pain is then I might not get up. I don't feel like doing that so I get up and do the old routines that I've always done"*. In addition, the maintenance of daily activities distracted the older adults, which in turn helped to lower their awareness of the pain. The woman continued to say *"When I start doing something else I forget about the darn pain…I sit down with my crossword puzzle….Then I've forgotten about the pain. Don't think about the pain. It's difficult but it works"*.

A major part of balancing the pain involved using medication as prescribed by the physician on a regular basis and taking extra when needed. The older adults felt that their medication to some extent relieved their pain, even though they did not become free of pain. The pain varied which made it difficult to foresee in advance the extent to which their medication would relieve their pain or if they would need to take more. In times when the prescribed medication was not enough there was a wish for something else to help them to endure. One woman said:

I take Paracetamol and then after half an hour or so it usually starts to help I think, I feel a little better but it doesn't help every time....It comes in periods…it moves about in the body and can't be ordered when to come but it comes when it comes and then one has to try to help and have something to take….If only one could get help to get a more tolerable situation when one gets these periods when one feels really bad and has pain.

In addition, some of the older adults considered aspects such as the dose and its effect on their body in the long-run. One woman said she had been told by health care providers *"that I can't take too much since that tablet won't help either"*. There was a fear of becoming dependent on the medication and concerns about possible effects on the body and the relief of pain. The woman continued, *"I'm scared to become dependent on them so that I would need more and more…and I'm scared that I would become dizzy from them, a little crazy. It might not help in the end anyway if I take more and more pain medication….Maybe it will get worse….I don't take more than absolutely necessary"*.

The older adults also balanced their thoughts and emotions to endure their pain in daily living. They tried their best to direct their thinking to stay as positive as possible in their current situation. One woman said *"I have a fairly good attitude and I want to believe that; oh I must be able to handle this. No one else can take the pain away from me, for me, this I need to deal with by myself"*. The older adults tried to dismiss thoughts of pain like expressed by one woman *"I'm always in pain…but I dismiss it. I try to think that: No, I'm not going to pay attention to it, I don't feel it"*. They also tried to keep the pain from effecting their mood which was described in words like *"I try to avoid crying, getting sad and feeling distressed"* even though sometimes *"the tears are never far away, but I know I can't let them come….the worst you can do is to sit there and cry and be sad….It is the worst you can do to give up on yourself"*. Furthermore, some of the older adults had found out that their state of mood influenced their notion of pain. One woman said *"I mustn't be too sad, if anyone makes me very sad you*

know, then it's as certain as amen in the church that I feel pain. It's like what the soul can't stand, the body has to bear".

This balancing of pain with activity, thoughts and emotions helped the older adults to endure their pain in daily life while trying to make the best they could out of their current situation. The balancing to endure their pain was permeated by learning on their own through trial and error.

Self Talking

The older adults carried on an active dialogue with themselves about their situation and how to endure pain in their daily life. This was different from when they were channeling their thoughts and emotions in a specific direction in order to keep themselves balanced and positive. The self talking was a purposeful cognitive way they had learned could help them endure their pain. The self talk theme shows the purposeful thinking, discussion, arguing and negotiation with self that was going on in the older adult's daily life when living with pain. It shows the conscious active dialogue that was going on with themselves in their situation about how to live with and endure their pain. This is different from the theme taking the pain as it comes, which constitutes more of a description of what they actually did to learn to endure living with pain, and not how they reached what they intended as in this self talk theme. It is also different from the balancing theme which illuminates that the older adults were channeling their thoughts and emotions in specific directions to keep themselves balanced and positive. The presence and intensity of this self talking varied. For those who had decided to not pay so much attention to the continuously ongoing pain, the self talk was less extensive than for those who described the influence of pain in their daily lives as challenging to capitulating.

One woman described how she had argued with herself about whether or not anything could be done about the pain since she wanted to remain in her home as long as possible rather than go to a nursing home. She declared to herself "*…and hasn't it helped by now during these two years, then there is no one that can do anything".* She then goes on to tell herself:

…so then I have to continue and have this pain as I have…one learns, that's the only word I can say… And I'm not the kind that is ill-tempered and angry and so on, I'm not, I'm just, I'm just reasoning so that there is nothing to do about it, that will have to be that. And if I get very much so that I become totally confined to bed then they, someone has to take care of that. That's just the way it is. I would rather live here and have this pain as I have then to come to a nursing home among all who have pain….As long as I can manage by myself, I want to do that.

For others, the self talking was more like an on-going dialogue or a constant companion, throughout the day. It helped them to endure by learning to live with pain in a way that they could keep on living a daily life. For the following woman, it was almost like she was her own coach, telling herself to put up with the pain, not be passive, move and fight to do what can be done. She declared:

One has to put up with everything…there are things that are much worse so to speak…sometimes one thinks it is unbearable…but that's how it is…one tries to move about and take care of the little one can do, one doesn't sit passive…one just has to submit to it and do the little one can do.

Sometimes the older adults actually negotiated with themselves in order to gather the strength needed to just exist and get through the day. Below one woman talked about how she talks herself into getting up and into the kitchen to make coffee. This was associated with difficulties and pain but sometimes she negotiated with herself to try anyhow. She told herself that she needed to make coffee and that it would cheer her up once she has had this cup of coffee.

Sometimes when I'm about to make coffee…I have difficulty with that but sometimes I try since I feel it will cheer me up, and then one fights to get that water and coffee going and to get that cup of coffee and then it feels a little better. One has to fight like that many times with everything.

This self talk was used to guide the older adults through the pain and daily living. They discussed how to proceed, convinced themselves to fulfill their intensions and negotiated when they needed to pull themselves together to do what they intended to endure by learning to live with long-term musculoskeletal pain in daily living.

Trying to be Less of a Burden to Family and Others

The older adults in this study tried their best to not burden their family and others while learning to endure pain in daily living. They continuously tried to be less of a burden and had learned by thinking in certain ways and using various behaviors to accomplish the intended the best they could. They did not ask for more help than absolutely necessary and had learned to find ways to do things themselves and by that, delay the day when there was nothing else to do but to allow others to help. When that time came, they tried their best to alleviate the situation for their family and other caregivers. One man said *"I do what I can and the wife does the rest and it works very well….I'm so afraid that it will be too much, too much for her….I try to be as neutral as possible to not put a burden on her since I know that she has much to do and that it becomes burdensome, it has worked very well so far".*

The older adults did not want to complain and bother family and friends with their problems. They endured and carried their thoughts and emotions inside themselves as much as they possibly could and avoided talking about their pain with others. They wanted to convey the message to family and friends that the pain was not so bad and that they were doing pretty well or even good in their situation.

I think that I never want to complain you know, so I carry it within me….I think that it doesn't get any better if I keep on talking about it… On the contrary, I want to be happy, so I don't show anything...I never talk about that I have any pain.

Several of the older adults had learned that nothing good came from complaining, for themselves nor in relation to others. One woman said that her son had told her *"don't nag mother because then I won't come and visit you".* She continued:

We know exactly where we stand so there's no hard feeling. I have said that I will never do anything that will make the children suffer because of me. I know what they have to do and they should have some pleasure in their life, the free time they have….But the children tells me now that; 'mother if there is anything you know you can call, if you are feeling alone and want to get out and so on'. But then, if one doesn't feel like one has the strength, it's no fun for either one of us.

Clearly, the older adult did not want their families to worry about them, since they felt that their children and their families had enough to deal with themselves. They wanted them to find joy and have a good time whenever they had a chance. In the interviews it was as though the older adults knew that they their families cared about them and that they could ask for help when needed. The notion of caring families however, did not change the older adults need to learn to endure living with pain on their own.

The older adults stayed home or avoided visitors when they felt that the pain was too difficult. They wanted their family and friends to have a good time and not focus on and attend to the older adults' needs. However, when participating in family events and the pain became worse, some of the older adults pretended that the pain was not so bad even though they in fact found it almost unbearable. Sometimes they went hiding for a moment to pull themselves together and get hold of the situation. However, how successful the older adults were in convincing their families and friends that they did not need to worry varied. As one woman said:

I want to be seen as being happy, first by my family and then by my children…When they come to visit I absolutely do not want them to see that I'm in so much pain. But they hear me when I moan and groan and am sad….I don't want to be a burden to them…they have enough to deal with themselves, they have difficulties with pain and suffering and they also have to have enough strength for their families….But they tell me that they see it, that I pretend to feel so good. 'You're just pretending mom', and I said let me pretend. Because I feel better myself when I'm pretending.

The older adults had learned how to think and used certain behaviours in their effort to be less of a burden to family and others. With varying degrees of success, they tried to conceal their pain and how they felt by not complaining and even at times pretending in front of families and friends. They wanted their children to have a good life and tried to facilitate that by trying their best to endure and to be less of a burden in their lives.

Capturing, Enjoying and Valuing Moments of Pleasure

The older adults consciously tried to capture, enjoy and value moments of pleasure. They had learned that it helped them to endure pain in daily life since such moments alleviated their pain, added meaning in life and gave them strength to carry on.

Occasions as when being asked to participate in social events and to spend time with family and friends to the extent that was possible in each older adult's life, made their day and life lighter. One woman said:

They do so much for me, clearly I value that and I think it makes me happy. This winter we had bingo down in the basement every other Thursday and then this woman came up to get me and said: 'You will come even if I have to carry you, you'll come'. It lightened up the situation only that she said those words and that I could participate down there and then she followed me back up here to make sure that everything worked out well for me.

When the older adults had the strength to meet with family and friends, they felt that their pain was alleviated for a moment and they even could forget about it for a while. This is illustrated by the following quote: *"It eases a little, clearly I'm always in pain but definitely it comes to be in a totally different way when I'm among people. I don't sense it quite so hard".*

For these older adults, their families were a major source for bringing joy and meaning into their lives. Their families called, visited and were many times the ones to see that the older adults got outside their home. The older adults were curious about and wanted to follow what happened in the lives of their families. As shown in the quote below, there were older adults that considered themselves to be living on overtime, but even those had learned to keep trying to capture and value things they found good about their life.

I'm so curious and I love my son so I don't want to leave him, that's why I got to be so old. I have lived 6 years too long….But I have a very wonderful son, he comes and does the shopping and then he takes me out sometimes…that is such an elixir and I live many days on that.

Memories from the past, but also more recent memories from life with family and friends were something that the older adults valued. These memories gave them something to hold onto and live for the current day and in the days to come. When evaluating their lives, many of them thought that they could not expect much more of life and realized that it was as good as it possibly could be, when taken into account the circumstances of their current situation. One woman concluded:

Many times I think that I've lived my life so I have to be grateful for what I've got....I think that everything works so well so I think I require no more….Yes we have had a good home in every way, family circumstances and everything. I think that one lives on that one has had such a good life....Many times one sits and think back upon life. I sure have pleasant memories and that one lives on.

For these older adults capturing, enjoying and valuing moments of pleasure was a way they had learned helped them to endure pain in their daily life since it to some extent alleviated their pain and helped them to keep their spirits up, gave strength and meaning in life.

Discussion

Clearly, it is a challenge to alleviate the older adults' suffering and meet their individual needs while living daily life with pain at home. The older adults' overall orientation and first priority was to continue daily living despite pain and not the pain itself. They focused on how to live with musculoskeletal pain and had realized that there was no other way out than to endure and learn to live with this pain in their daily lives, an orientation which contrasts with much of the existing literature on pain. Undoubtedly, musculoskeletal pain has been recognized as global and increasing health problem overtime. However, the existing literature predominantly focuses on prevalence, causes, management, associated disabilities (physical, psychological and social) and the burden on society with reference to economic costs [4,5,9,22,29,44-46]. Unfortunately, there is limited literature about how community dwelling older adults actually live with this type of pain, which would be valuable knowledge for health care providers. The image in the literature does not reflect the fluctuating nature of the pain nor provide a detailed description or guide for how to live with this kind of pain in one's daily life. In this study, the older adults' pain was anything but constant and they had to work hard to figure out how to endure it on a daily basis. The learning had become integral to life itself like described by Berglund [47]. The notion of learning as a component in life with pain was illuminated Sofaer et al. [32]. However, the predominant focus on learning in the act of enduring pain has not been found in earlier studies. Neither has the constraint associated with this learning among the older adults in their effort to fulfill expectations and demands from self, relatives and health care providers.

Clearly, endurance by learning to live with pain without any established guidelines was a challenge for these older adults. They used trial and error and overtime learned that balancing activities, thoughts and emotions was a necessary element in daily life. Fagerhaugh and Strauss [48] referred to balancing as a process of making choices to control actions and argued that it might be the most important process in relation to understanding interactions involving pain. The participants in this study deliberately balanced their pain and disability in relation to planned activities for the day [48,49] and evaluated the advantages versus disadvantages of any one activity [33,34,47]. The balancing was

not only related to physical activities and certain moments during the day. It also was a continuous ongoing process with deliberate choices being made throughout the day, including not just the physical dimension of balancing but also a psychological dimension, one related to the balancing of thoughts and emotions. The balancing was oriented both internally (balance within self) and externally (balance towards the surrounding world) similar to that described by Lipworth et al. [50]. Berglund [47] described this act of balancing as "the way to learn" which constitutes one of the components in "the essential meaning of learning to live with long-term illness" (p. 189).

Furthermore, little attention has been given in the literature to expectations and demands of health care providers and others on the older adult's ability to be independent. The older adults in this study had learned to endure living with their pain pretty much on their own even though they had received various degrees of support from health care providers. There were no detailed descriptions or any guidelines available on how to live with pain in daily life, so trial and error was used until something was found that worked. The demands placed on patients by health care providers were similar to that found by Wiener [49] in a study of participants who described the uncertainty they had to contend with in relation to the pain associated with rheumatoid arthritis. The adults in Wiener's study faced the demands in managing their life with an incurable chronic disease associated with unpredictable pain and were often told by physicians that "You're going to have to learn to live with it" (p. 98). The need of improved information, empathy and guidance by health care providers to manage pain as acknowledged by the older adults in this study is similar to findings in a study among adults 40 to 65 years by Dewar et al. [51].

The management of pain was not satisfactory for the older adults in this study. This experience might be associated with research where long-term pain among community dwelling older adults is found to be frequently unrecognized, underestimated, underreported and undertreated [10] which might lead to older adults` suffering in silence [52,53]. The older adults in the study had to endure continuous and fluctuating pain daily and had concerns about their pain and its relief now and in the future. It seemed that the health care providers recognized the lack of satisfying pain relief but were not able to provide any more help. Patients reported that they did talk to their health care providers about their concerns and that they felt they could take the pain anymore and needed help. In turn, the health care providers tried to encourage the patients by saying that "they could do it" and that they needed to be satisfied with the help they had received. The older adults in this study had a feeling of being on their own while learning to endure pain in daily living. This experience contradicts the prevailing centrality in nursing to help individuals live in their context and the existing guidelines for management of long-term pain among older adults aimed at preserving the older adult's dignity, function and overall quality in life [54-57]. It can be assumed that the experienced lack of pain management and support might be associated with the tendency documented in the literature where pain is expected as an inevitable and natural part of aging [58]. Thus, this notion has been refuted in the literature [59]. However, the opinion of this type of pain as a natural part in the process of aging was prevailing among the older adults in this study. From their experiences one might assume that the healthcare providers involved tended to assume the same.

The difficulty for older adults living with musculoskeletal pain, to achieve adequate pain relief has also been acknowledged by Von Korff [13]. Yu et al. [60] addressed the limited literature about the strategies used by community dwelling older adults to relief long-term pain. The authors argued that nurses need to acknowledge this problem and provide older adults with guidance about strategies for effective pain relief. This was clearly the case for the older adults in this study. They acknowledged the need of improved information, empathy and guidance by health care providers to manage pain in daily living based on each individual's experience. However, this need can be understood as not being dependent of age since it is similar to findings in a study among adults 40 to 65 years, by Dewar et al. [51]. Furthermore, Von Korff [13] highlighted the need for health care providers to tailor the pain care and promote self-management based on each individuals' experience to improve quality of life. Spiers [61] emphasized that a central role for nurses in the management of the older adult's pain is to listen, communicate and respond to the expression of pain with a specific focus on the experience in each individual's current situation.

However, there is a well-known existence of stoic attitudes among older adults result in a reticence to report pain [58,62,63]. This stoic attitude may in part explain why older adults used self talk, where they discussed, argued and negotiated with self and their environment to get themselves to do what they felt they needed and their effort to be less of a burden to family and others. The reluctance to complain about pain and not disturb others has been recognized in other studies [64,65]. In addition, findings from research studies have shown that older adults want to spare and not upset their relatives [53], nor involve or burden their families with their health care needs [65]. Not being a burden can also be viewed in light of Wagstaff and Rowledge's [66] concept of stoicism which includes three measurable characteristics: "lacking of emotional control or endurance", "lacking in emotional expression" and "exercising emotional control or endurance" (p. 181). The force to not complain, disturb or be a burden to family and others was strong among the older adults in this study. The reluctance to talk about their pain can be understood in light of findings in the studies above. The purposeful act of pretending to not be in pain can be understood as novel in the older adult's endurance of pain. This conscious action to give a false impression about the experience of pain has not been recognized by the authors in earlier studies.

It may be that the older adults in this study were to various degrees stoic while learning to endure pain in daily living. However, reasons behind this stoicism may not only be intrapersonal. It might also be influenced by external factors, such as expectations embedded in ongoing interaction and negotiation with others and the environment. In fact, the stoicism might be an effort by older adults to prevent becoming distanced from others. From the perspective of the negotiated order [67], older adults live within a mutual negotiated order which most often is implicit and involves tacit agreements or understandings. In this study, the families and health care providers had implicit and explicit expectations and demands that the older adult tried their best to fulfill in order not to be a burden and become distanced. Language is way to convey these expectations. Clearly, there is a need for health care providers to reflect upon the language used in their conversations with older adults. Language that might be intended to support can in fact be a source that creates isolation and adds to the sense of being a burden.

The importance of support and guidance over time based on the individual's context has been highlighted by Berglund and Källerwald [68]. Such guidance was seen as a prerequisite in the process of learning to live with long-term illness involving both coping and conscious reflection in everyday life. This aligns with Kim's [69] emphasis on nursing practice that "encompasses both the scientific problem-solving orientation and the human practice orientation. Nurses are not only dealing with and seeking solutions for clients' health problems but also

are concerned about how to help clients in their "living with" certain health-related situations [69] (p. 2). Kim [69,70] introduced the concept of human living which encompasses the environment, interactions and phenomena in the client's life and argued that helping and supporting individuals in finding ways to live their lives while dealing with a health problem and within the health care system is central to nursing practice.

Furthermore, nurses need to take into account that these older adults, to varying degrees, live in a negotiated reality where they are used to making agreements. Nurses need to take time and be there with the older adult in the home and make collaborative decisions, even if this includes some negotiation [61,71].

The older adults tried to maintain the relations and support they needed and valued from family, friends and health care providers in order to learn to live with their pain and still remain at home. The older adults, within the context of a negotiated reality [72,73] tried to focus on things that gave meaning and strength in life, such as capturing, enjoying and valuing moments of pleasure. The older adults in this study had learned that moments of pleasure could be a distraction and lessen the intensity of pain, similar to that reported in other studies of individuals with long term pain [74-76] and often espoused as a noninvasive method of pain control [77]. However, for these adults, these moments were more than simply a source of distraction. They kept their spirits up, gave them strength and meaning in life, a finding unrecognized in the literature on long term pain, although hinted at by

Stenström et al. [78], Tollen et al. [79] and further described by Lerdal et al. [80] in studies of individuals with disabilities and long term illnesses. It would appear that learning how to endure living with long-term pain in daily life is not limited solely to gaining knowledge and skill in using pain management strategies. This is an important, novel aspect that contributes to the existing literature since traditionally health care providers have focused on older adults problems and negatives in life. Sensitivity and an understanding of the things that bring joy and give strength and meaning in the older adult's life could help to address the older adult's experience and needs while learning to endure pain in daily living.

Methodological Considerations

Similar to Lincoln and Guba [81], Graneheim and Lundman [41] use the criteria trustworthiness to secure credibility, dependability and transferability in their approach to establish what traditionally is called validity and reliability in the quantitative paradigm. These criteria were used in this study to secure and enhance the quality of findings in the study.

Limitations in this study include the issue of trustworthiness. The credibility can be questioned since the sample size in this study was small, even though this is consistent with qualitative research in general. In addition, the sample was homogenous in large part because the majority of the participants were native speaking Swedish women who lived alone in their homes in small to midsize communities. Unfortunately, it was not possible to shed light over this experience from an equal gender perspective, even though consistent with the demography in this population. No member-check was performed; however it was offered but denied.

Despite the limitations above trustworthiness was focused on throughout the study, as consistent with the chosen approach. The face to face qualitative interviews with momentarily and continuous confirmation of the participants' verbal and nonverbal expressions, gave a thick descriptions of the participants experiences which enhanced the credibility of the study [39,40]. Efforts to further enhance the credibility were made when the participants were given time to reflect upon if there was anything they wanted to add before the interview was ended. Even though denied, each participant was offered the opportunity to read the transcribed interview.

Furthermore, the credibility was strengthened through that the researcher stayed close to the text during the analysis to not lose the core in the content. It was only those aspects of the text related to the aim that were sorted out, condensed and abstracted into codes and themes. The themes answered the research question and the experience of enduring pain by learning to live with it permeated the five themes as an underlying meaning, both explicitly and implicitly, which strengthened the credibility of the themes. Additionally, examples drawn from the data in each step of the analysis were presented to enhance credibility. In addition, representative quotes were used to illuminate the theme and sub-themes to strengthen the credibility of the findings. Furthermore, the close communication between the first and second author in the phase of labeling codes and creating themes and sub-themes strengthened the credibility and dependability of the study.

The transferability of the findings in terms of generalization to all other adults in living under similar circumstances cannot be claimed by the authors. Although, the obtained rich description of the older adults' experiences give an understanding of how older adults endure living with this type of pain in the context of home. Stake [82] argue that the potential for qualitative findings to be transferred is determined by the reader since it depends on how the findings can be related to the readers' context, knowledge and earlier experiences. This argument support that these finding can be useful for health care providers familiar with this population and context. The findings can be used to guide the planning and provision of individualized care for older adults living at home with musculoskeletal long-term pain. These findings can also be used as a reference point and compared with findings in current and future studies to confirm and further develop the understanding of this experience in various contexts.

Conclusions

The older adults in this study felt there was no other way out but to endure and felt forced into learning to live with their pain. However, their primary orientation was not the unpredictable pain itself. Their primary focus was on learning how to endure daily life with pain and to coach themselves, with a minimum of guidance, while still remaining as independent as possible at home. The continuous interaction and negotiation with self, others and their environment was useful in their learning and coaching. The force to not complain, disturb or be a burden was strong and the purposeful pretending to not be in pain can be understood as novel in this context. Another important and novel aspect was the older adults' orientation towards seeking out things they valued and moments of pleasure in life. This was important and since it gave them meaning in life and strength to continue.

The older adults in this study highlighted the lack of support and guidance in learning how to endure and live daily life with pain. This calls for increased sensitivity, empathy and willingness in the interaction with the older adult. The care need to be oriented towards not only each older adult's needs in life related to the current health problem. It also requires an orientation with focus on existential issues as the older adults' values and meaning in life. The overall orientation in providing health care for older adults needs to be aimed at providing tailored, holistic and individualized health care that preserves and

promotes health and well-being with a maximum of care and a minimum of intrusion.

Implications for Research

Further research is needed to bridge the gap in the literature between existing writings that acknowledge the increasing burden of this type of pain worldwide and the need to focus on how older adults endure living with this type of pain in daily life at home. Furthermore, research is needed to explore and describe the older adults need for guidance in learning to endure pain in daily living and how that guidance might be designed or conveyed. In addition, there is a need to further explore the older adult's seeking out moments of pleasure and meaning in life.

Acknowledgements

Thanks go to Professor Hesook Suzie Kim who, together with the late Professor Björn Sjöström initiated the Joint PhD Program in Nursing between University of Skövde, Sweden and The University of Rhode Island, USA. Acknowledgments to the Skaraborg Institute for Research and Development and the School of Life Sciences, University of Skövde, Sweden for grants and support. Thanks also go to the older adults in the study.

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Citation: Gillsjö C, Schwartz-Barcott D, Bergh I (2013) Learning to Endure Long-Term Musculoskeletal Pain in Daily Life at Home: A Qualitative Interview Study of the Older Adult's Experience. J Gerontol Geriat Res 2: 136. doi:10.4172/2167-7182.1000136