RESEARCH ARTICLE

The Construction of Coping of Adults with Rheumatoid Arthritis

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Abstract

Purpose: People living with diseases where symptoms are not visible to the naked eye, such as Rheumatoid Arthritis (RA), are frequently misunderstood by the public and consequently face numerous conflicts in their lives. The study aims to develop an explanatory framework towards the constructions of coping of adults with rheumatoid arthritis (RA).

Design: The study made use of the Straussian Grounded Theory Method. 15 adults with ages ranging from 21 to 50 years old, diagnosed by a licensed physician with rheumatoid arthritis for at least six months at the time of the study, with an active social media account, and are in the convalescence or remission phase participated in the study. The study setting was based on the participants' preferences within the National Capital Region, Central Luzon, and Calabarzon areas. This study has been reviewed and approved by UP Manila Research Ethics Board (UPMREB).

Methods: Purposive sampling and theoretical sampling were used in selecting the participants. Unstructured interviews and observation played central roles in the data collection. Consistent with the Straussian Grounded Theory method, the analysis was based on data immersion and iterative open, axial, and selective coding.

Findings: The constructions of coping in persons with Rheumatoid arthritis was presented through a “coding paradigm” of causal conditions (disconnect and invisible suffering), context (isolation and psychosocial burdens), intervening conditions (cultural values and family attitude, values, beliefs, and dynamics), strategies (joining online RA group and sticking with people who understand), and consequences (regaining control and helping others with the same condition) which were further explained in this paper.

Conclusion: The study presents experiences of persons with RA and their constructions of coping, shedding light on the often-misunderstood course of symptomatology and the struggles the afflicted persons go through. Despite having social media as the milieu by which these concepts emerge, this study's theoretical model may help health practitioners understand persons afflicted with diseases with imperceptible symptoms. Understanding their experiences in the context of the theoretical model presented could suggest information and support modalities for these groups of people.

Keywords: *Rheumatoid arthritis, invisible symptoms, constructions of coping, online support group (OSG)*

Introduction

People living with diseases where symptoms are not visible to the naked eye, such as Rheumatoid Arthritis (RA), are frequently misunderstood by the public and consequently face numerous conflicts in their lives. The absence of observable signs of illness in adults with RA often puts them in a misunderstood stance. The misperception drives them to act and decide in ways that further reinforce their isolation (Yao et al., 2015).

The invisibility of symptoms in a chronic illness may drive individuals to try different things to cope. They may participate in social actions and have a better understanding of their experiences, all of which can be constructive events in an individual's illness journey—(Frank, 1995 as cited in Phillips & Rees, 2018).

This study explains the constructions of coping of adults with rheumatoid arthritis (RA) and the theoretical model for coping that emerged from the data. This study was initially intended to discover the concepts of social contagion by grounding the idea of the influence exerted by social media friends on a person with a chronic or debilitating condition that results in positive changes in health behavior.

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However, in data gathering, theoretical sampling, and data analysis, themes emerged to shed light on another dimension in the use of social media by adults with RA and how they use such facilitated coping. The interview questions were aimed at understanding the role of social media friends in their change of behaviors. However, results of data analysis highlighted the challenges adults with RA encounter given the invisible symptomatology inherent to the disease. The results also show how the resulting negative reactions from their immediate social circle (family and friends) both online and offline, their isolation and psychosocial burdens, and their individual cultural and family characteristics gave meaning to the utility of an online support group (OSG) to their coping.

This study takes theoretical inspiration from Irvin Yalom and Molyn Leszcz's book, the Theory, and Practice of Group Psychotherapy. Yalom's study of and practice in group therapy led to identifying eleven therapeutic factors that result in significant changes and shifts for group members. Yalom (2005) believed that group therapy is responsible for fostering a culture of cohesiveness, support, and integration. "The interaction between group members provides the mechanism for change. By living existentially, clients learn how to accept these conditions without escaping from them. Instead, they learn how to live with them and through them (Yalom & Leszcz, 2005)."

In a qualitative study done by Peirce, Haw, and Otter (2018) in the United Kingdom to explore the use of social media and apps by people with rheumatoid arthritis, users create and link networks of people with shared interests/ experiences in a user-centric and collaborative manner, which could play an important role in patient-centered care. The same study highlighted the need to identify new methods of support for women whose lives were extremely disrupted by RA. Social media often filled this role as the use of Facebook or Twitter allowed contact with people with similar experiences in a much wider geographical area (Peirce et al., 2018).

The invisibility of symptoms of Rheumatoid arthritis puts the afflicted in an often-misunderstood stance which pushes them to withdraw from and avoid family and friends who cannot fully understand their health condition. It is crucial to understand how adults with RA cope, given the circumstances that surround their situation. This study developed an explanatory framework towards the process by which adults with RA move from their negative and positive experiences to being able to cope. This context has not been adequately explained in previous studies on invisible symptomatology, coping, and social media.

Methods

Design

The study adopted the Straussian Grounded theory method for its clear and systematic structure which proved useful to the researcher, who is a beginner in grounded theory study. The method established the theoretical basis for the concepts in the study. The Straussian method helped in balancing the shortage in existing studies that fully explain the relevance and relationship of invisible symptoms, coping, and the use of online support groups. The method also helps support its use for the population under study. The nature of the research questions towards action and processes makes the Straussian approach the best methodology for this study (Vollstedt & Rezat, 2019).

Context Setting

Participants who know the phenomenon being studied were identified and approached for the study. Due to the nature of the sampling method used, the study setting was dictated by the participants' preferred locations. Study settings ranged from workplaces to coffee shops and restaurants in malls near them and waiting areas of doctor's clinics. These settings are mostly in the National Capital Region (Metro Manila: Quezon City, North Caloocan, Manila, Makati, Marikina, Pasig, Rizal), Central Luzon (Region III: Bataan, Pampanga, Zambales), and in Calabarzon (Region IV-A: Cavite).

Sample

Fifteen adults with ages ranging from 21 to 50 years old, diagnosed by a licensed physician with rheumatoid arthritis for at least six months at the time of the study, with an active social media account, and are in the convalescence or remission phase participated in the study. Participants in the convalescence or remission phase have an increased likelihood of active participation than those in the acute or exacerbation phases of the condition.

Purposive sampling was initially employed. Participants who know the phenomenon being studied were identified and approached. As themes begin to emerge, theoretical sampling ensued. This means analysis of the data informed sample selection (Glaser and Strauss, 1967).

Ethics, Privacy, and Confidentiality

This study has been reviewed and approved by UP Manila Research Ethics Board (UPMREB), a committee whose task is to ensure that research participants are protected from harm. The same Board approved the use of the Informed Consent Form in English and Tagalog, which were presented and explained to participants prior to data collection. The highest level of objectivity in discussions and analyses was maintained throughout the study.

The following procedures were done to reduce the risk of data breach and maximize confidentiality, namely, unnamed memos and transcripts, password-protected raw and processed data.

Only important data were shared with the UPMREB, the conduct of regular self-audits vs. the steps of the Straussian Grounded Theory method, and non-solicitation of private information not necessary and relevant to the research question.

Data Collection

Face-to-face unstructured interviews played a focal role in collecting data for this study. Data gathering methods other than interviewing, such as observation and memoing, were used to help develop the theoretical model. The researcher gained access to an online community of Filipinos with a debilitating condition known as rheumatoid arthritis through Facebook (FB) by joining the group. The researcher was admitted to the closed Facebook group because she has Rheumatoid Arthritis, too. Upon establishing rapport and gaining permission from the FB group administrator, individual members were sent private messages to explain the study and invite each of them to a face-to-face interview. Arrangement of meeting places, times, and dates was made online through FB Messenger. Additionally, the consent of a licensed rheumatologist and immunologist was obtained for the researcher to approach potential participants for this study in the doctor's clinics in Manila and Bataan. Data collection was done in a span of 16 weeks (4 months) from August to November 2018 and was scheduled at a time, place, and day convenient to the participants based on the researcher's projected timeline.

Each of the 15 participants participated in a 30 to 40 minutes in-depth, unstructured interview and was shortened or prolonged based on the participants' condition at the time of the interview. Two open-ended questions were asked to guide the conversation loosely: (1) Can you tell me about an incident when a social media friend sent you a message about your illness, and how did you feel about it? (2) Did you think there was a message sent by a social media friend that influenced you positively? Please tell me how. Relevant questions were raised in attempts to obtain rich data from the participant. The interviews were documented using audio recorders and memos.

Instrument and Technology

The researcher used an anonymized information sheet for gathering pertinent demographic information from each client. A digital audio recorder was used with consent to record the interviews. The researcher made use of a notepad intended solely for the use in the study to take down notes and to write down memos. The instrument and device remained constant throughout the study.

Data processing

The analytic process was based on transcripts of comprehensive, unstructured interviews and the researcher's memos. The data consist of four months worth of recorded interviews with participants equivalent to more than 300 minutes of audiotapes.

All the digital audio recordings were transcribed unabridged, word-for-word by the researcher. The data was composed of over 60 pages of transcriptions and memos. The data was stored in the researcher's password-protected personal portable computer.

Data Analysis

The analytic process started with the data collected on the first interview. The researcher analyzed the first fragments of data for cues. Each concept repeatedly present in interviews and observations was retained (Corbin & Strauss, 1990). Analysis was based on the Straussian Grounded Theory method of open, axial, and selective coding.

The open codes identified were invisible pain and suffering, triggers/sources of frustration, negative effects of the disease (RA), contradicting role of immediate family members, motivations for online use, same situation identification, affordances of online support group (OSG), and positive effects of the disease (RA). The two major axial codes identified after establishing relationships among the open codes were Drivers for Action and Taking charge. The main thematic category that emerged from the main theme's systematic alignment with other categories is coping.

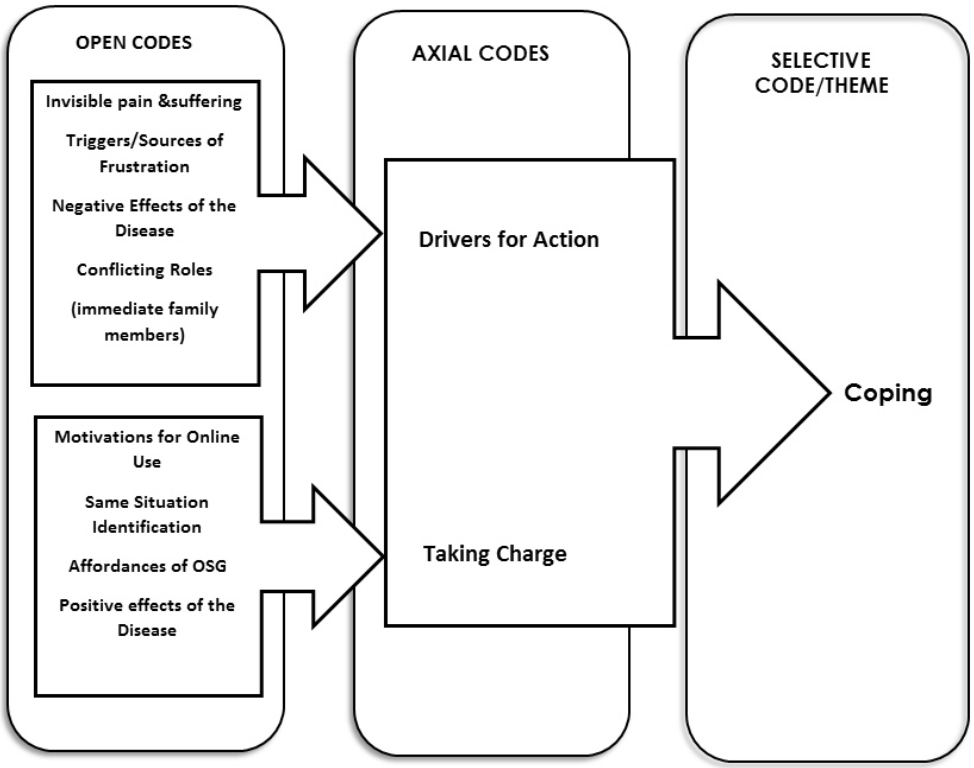
Techniques to Enhance Trustworthiness

The researcher established trustworthiness by making the utmost effort to achieve credibility, transferability, dependability, and confirmability through methods and sources triangulation; explicit description of the sample, participants, methods, and the research setting in the methods chapter; and by preserving reflexivity.

Results

Thirteen females and two males willingly participated in the study. Among the fifteen, five are married, five are single, three are separated, and two live with partners. Most participants, whether married, separated, or living with partners, have adults and teenage children. However, three married females have the additional challenge of tending to small children. One with a disability – 33 y/o Beatrice has a five y/o son, 35 y/o Sheena has two teenagers and three toddlers, and 41 y/o Anne has an 11 y/o son with autism. All names that appear in this study are pseudonyms to conceal and protect the identity of the participants.

Figure 1. ***Representation of the Coding Process from Open to Selective Coding***



All participants appeared in good shape, put together, and have no obvious signs of any physical suffering or disability except for Sylvia. She has been wheelchair-bound for the last three years at the time of the interview. Cathy needed the aid of a cane to walk and sit, while Lea limped and walked at a slower pace than the researcher. Dylan's deformed fingers, according to him, are a constant reminder of his grueling experience with RA.

All fifteen participated with enthusiasm. The excitement to speak to someone about their daily challenges and experiences was very palpable. The participants' willingness and eagerness pave the way for a rich sharing of experiences.

The results of this study will be presented through a "coding paradigm" of conditions, context, strategies (action/interaction), and consequences. Codified excerpts of data to describe each paradigm component are given to elucidate the results.

Causal Conditions Related to the Core Phenomena

Two causal conditions emerged from the data ie., the disconnect (social media friends without RA have with those with the disease) and the invisible suffering (of those with RA).

Disconnect

Disconnection from social media friends who do not have RA stemmed from their inability to understand the experiences and struggles of people with RA. They often dismiss the severity of symptoms because of the similarity with those of arthritis that comes with aging. Faye mentioned that friends without RA think it is just common arthritis. It is rare to find an FB friend who understands or would want to understand. While some of Beatrice's friends thought it is just common arthritis. She had to say she is afflicted with something similar to Lupus to highlight her condition's severity. Sheena found the teasing of her social media friends who do not have RA offensive and became sources of additional stress. For her, only those who go through the same situation are the ones who could understand what she was experiencing.

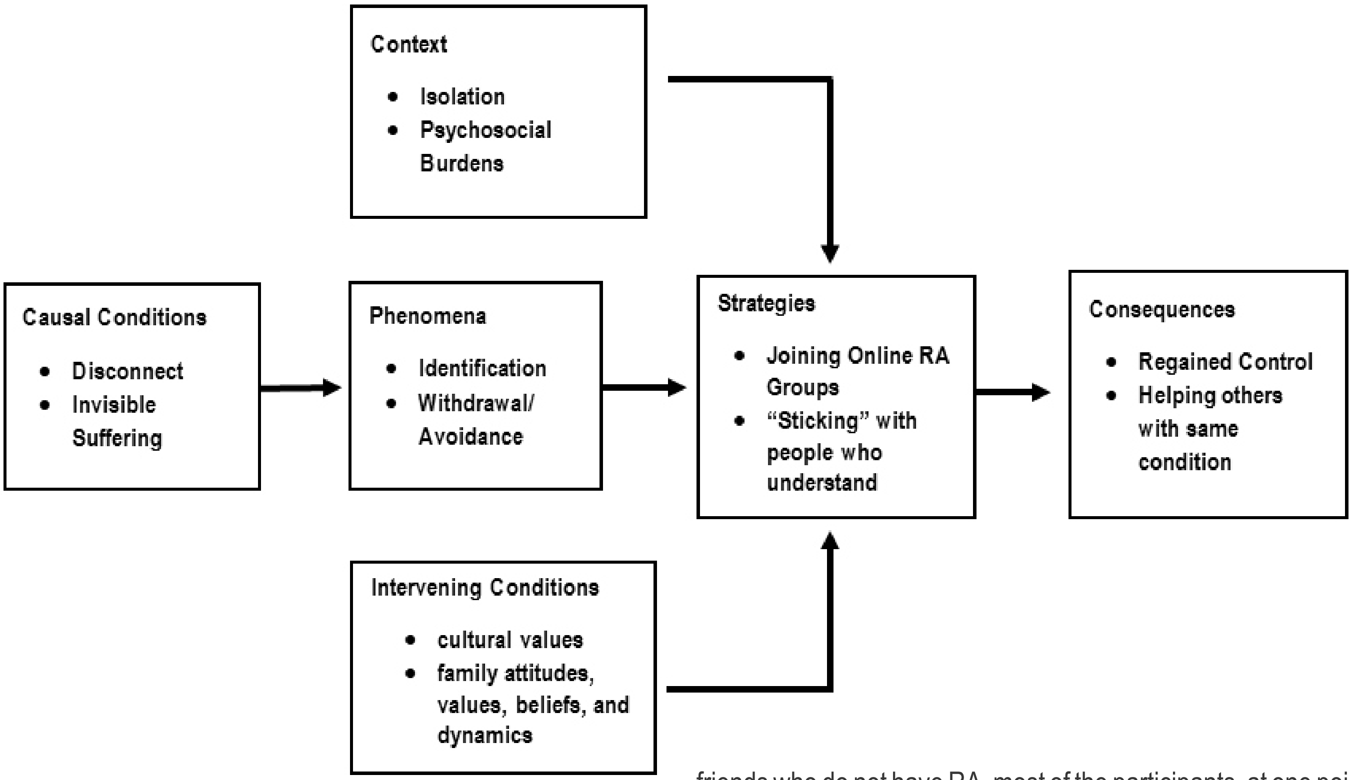
Invisible suffering (of those with RA)

The second causal condition is the invisible suffering of adults with RA because they often “appear normal.” The invisible suffering is a result of the invisibility of RA's symptoms.

Rheumatoid arthritis (RA) is a chronic progressive autoimmune disease characterized by inflammation of synovial joints, causing immense pain and joint stiffness. Patients with RA experience progressive deterioration of physical functioning, resulting in limitations in daily living activities and reduced functional independence. Patients with RA experience extreme fatigue and severe pain that restrict mobility and limit their ability to carry out day-to-day activities(Poh, et.al, 2016, p.2).

The covertness of the severity of pain to the naked eye puts adults with RA in a misunderstood stance for their seemingly normal appearance. The burden of explaining themselves and from hurtful remarks or messages makes them withdraw from or avoid engaging with them online. “We are not lazy, making things up, making excuses; there is pain that is not visible,” Anne said. She wants others to understand that the disability is not visible. On the other hand, Beatrice wants others to know what RA is and how they endure pain and that it is something unseen.

Figure 2. *The theoretical model for coping among adults with RA*



Phenomena Resulting from Disconnect and Invisible Suffering

The causal conditions of disconnect and invisible suffering gave birth to the core phenomena of Identification (with people who have the same condition) and Avoidance/Withdrawal (from those without RA).

Identification (with people who have the same condition)

Adults with RA tend to "identify" with and turn to social media friends who have RA too. The gravitation towards people who have the same condition resulted to joining an online RA support group. For Sheena, the online RA group helps share their stories, making her feel she is not alone. She finds hope, encouragement, and suggestions in the stories shared in the OSG. Lea searched for online support groups for emotional support. She said an online support group could support members losing hope, which sometimes she cannot get from her own family. Sylvia preferred RA online support groups for inspiration. She gets encouraged to bounce back from what was a seemingly desperate situation to almost being normal.

Avoidance/Withdrawal (from those without RA)

To reduce additional stress caused by remarks of social media friends who do not have RA, most of the participants, at one point in their lives, withdrew from social media friends who do not understand the nature and course of their disease. Jana did not want to post what she was going through on her FB wall and avoided her FB friends until she got better, so there would not be a need to explain her actions and avoid getting offended by friends about her condition and limitations. Lea stopped making her posts public because it created rumors and false information about her condition. She avoided her FB friends (spreading false information about her) to avoid being stressed by them and their remarks. For Cathy, she withdrew from her FB friends who do not have RA to avoid the pseudo-medical advice they give her, which was of no real benefit.

The Context in Which Strategies for Coping Developed

Participants' coping mechanisms were in response to their disconnection and avoidance of people who do not have RA.

These techniques were shaped by contextual indicators related to both the causal conditions and the resultant phenomena. These contextual markers were isolation and psychosocial burdens.

Isolation

Eight out of the fifteen respondents said they had lost their social life and self-esteem as a result of having RA. The difficulty in getting up from bed, more so, walking restricts their activities not only in social media but in their daily routine. Lea lost her social life out of the fear of being a burden to her friends and being ridiculed. Anne did not want to cause negative reactions or experiences because of her disposition due to pain, so she stopped attending occasions. Cathy became a loner because she is most of the time at home, in pain, and unable to perform the activities she previously loved doing, like going out on trips. All these factors and the loss of communication with friends, made the participants feel isolated, and consequently, several lost their self-confidence in the process.

Psychosocial Burdens

Rhea said with RA, you cannot avoid having anxiety & depression. Lea, Sylvia, Dylan, and Cathy reached the point of wanting to give up. They thought of ending their lives. They reached the point of hopelessness and would rather be dead. Cathy felt useless when she was stricken with RA and thought that her family loved her less. She has developed anxiety and has become paranoid. “I just want to be normal again,” Cathy said. Due to years of depending on others, Dylan developed the fear of being alone. He would panic at the thought of not having any companion at home. There are occasions he thought of ending his life but was either too weak or in too much pain even to lift a knife. Deena recognizes that people can get depressed out of pain.

Together with context, intervening conditions likewise influenced the participants' choices of coping strategies. Intervening conditions in this study included cultural values and family attitudes, values, beliefs, and dynamics.

Intervening Conditions

Cultural values

Cultural values of a religious nature related to hope were particularly influential. Sylvia believes miracles come in different ways. She considers those around her as part of the miracles & blessings in her life. Being wheelchair-bound since the onset of her RA, she does not focus on her physical limitations. On the other hand, Rhea was able to overcome anxiety & depression because of her spirituality and the spiritual community wherein she was a member. Prioritizing her spirituality was a big help to her. Lea turned to the church and her husband for positivity. Faith is a significant factor, she said. “I'd rather turn to God than to people. Prayer coupled with taking care of one's self is key.”

Family Attitudes, Values, Beliefs, and Dynamics

Rica finds even well-intended comments from family members offensive for lack of understanding of the disease course.

> “May kuya ako na parang iba yung thinking niya. Tapos syempre nagkaka sakit ako noon. Ang ayoko lang na narinig sa kuya ko ay yung hindi na makakapag trabaho yan, may rayuma yan. Ang gusto ko lang iparating, maging sensitive sila. Alamin naman nila yung mga sinasabi nila kahit anong klaseng arthritis pa yan kasi talagang masakit.”
>
> [I have a brother who seems to think differently. When I got sick, I did not like it when he told my mother that I might not be able to work and help the family because I have RA. What I want to tell them is to be sensitive enough and should choose their words carefully so as not to cause hurt]
>
> During the active phases of her RA, Beatrice had to distance herself from her three-year-old son due to the pain brought about by RA.
>
> “Yung anak ko hindi ko mahawakan. Kasi makulit. Konting ganon lang sa akin, aaray na ako, so mainit na yung ulo ko, so mapapalo ko na siya. So, nag di distansya na talaga ako.”
>
> [I cannot hold my son. When I carry him, and he moves about, I get hurt, and it makes me lose my temper, I end up slapping him, so I had to distance myself from him].

Strategies for Coping

Two predominant phenomena led to the development of parallel central strategies for coping together with the context and intervening conditions described above, namely joining an online RA support group and sticking with people who understand.

Joining an Online RA Group

Adults with RA find hope, encouragement, and suggestions in the narratives shared in the online support group. It gives them a feeling that they are not alone in their suffering. Online RA groups provided support to members who are losing hope, support that sometimes they cannot get from their own families. There were instances that family members do not understand their symptoms, unlike those who have RA. Adults with RA prefer to confide in FB friends who have RA too or to members of online support groups when in pain. The feeling of belongingness afforded by online support groups gives a sense of inclusiveness and hope to them.

Sticking with People Who Understand

Adults with RA “stick” with people who understand their predicament. These are mostly family members and those with RA, too. Sheena ventilates her predicament to her co-workers even if they do not fully understand her condition. It is of help to her that they recognize when she has a flare and the limitations it imposes on her work and functioning. For Lea, her husband was of great help and a source of encouragement. Deena's co-workers understand her dietary restrictions. For her, those who have no idea about RA are incapable of understanding and showing compassion. Faye's close friends and family are usually of help. She said, "It feels good to know that they know when I am not okay."

Consequences of Strategies for Coping

As a result of the strategies employed by adults with RA, joining online RA groups, and "sticking" with people who understand, the strategies led the participants to regain control (over a lost social life, self-esteem, etc.) and has prompted them to help out others with RA too. This is consistent with Yalom's work that being part of a group results in universality and altruism.

Regaining Control

Joining an online RA group has helped Anne understand the mental health issues that affected her and her husband as a result of her disease. Sheena, Jana, Lea, Anne, Cathy, and Faye felt validated and wanted to take care of themselves more when they realized through an online support group that there are other people with RA and that they are not alone in their suffering. Grace regained confidence in herself again when she had a better understanding of her condition through the doctor's help and her interactions with members of an online support group. Dylan created his own FB Page, a community/forum for Rheumatoid Arthritis sufferers and their families. The sharing and exchange of experiences made him more in tune with what he needs to undertake to reclaim all that he lost in the eight years when he suffered enormously. He has regained his mobility, sense of worth, self-confidence, confidence from his family and the people around him, and providing for his family to name a few.

Helping Others with the Same Condition

Another consequence is the desire to help others who are struggling with RA. People benefit through giving, not only in receiving help but also in gaining intrinsic value from the act of giving. "Many adults with RA, in the beginning, are demoralized and possess a deep sense of having nothing of value to offer others. They have long considered themselves as burdens, and the experience of finding that they can be of importance to others is uplifting and encourages self-esteem" (Yalom & Leszcz, 2005).

Dylan had RA in 2004 when there was not much available information and treatment about the disease in the Philippines. The progression of his RA was severe that he had lost his ability to walk instantly. He took it upon himself to learn more about his condition and searched the internet extensively for answers. Given the difficulty he was in for eight years, he felt it right to put up his own FB page on RA in 2012 as a way of giving back to people, strangers, even those who helped him during the time that he was lost and suffering. He wants to help those who might be in the same predicament as he was in 2004 through his FB Page. Joseph sympathizes with RA patients who suffer from pain so much that he wants to be of help. He shares how he manages his symptoms in the online support groups that he is a part of. While Grace purposely talks to friends about RA to make them aware as she would not want any of them to suffer the way she did. Rica, on the other hand, feels good that her RA journey inspires her peers.

Discussion

The present analysis is consistent with Yalom and Leszcz's work on the therapeutic factors in group dynamics.

People are troubled with thoughts that they are alone in their suffering. These unsettling thoughts are brought about by fears arising from their difficult experiences that may occasionally surface from their subconscious. Although this may be real for most people, countless have intensified sense of uniqueness due to severe isolation.

Their relational problems prohibit the likelihood of deep intimacy. In everyday life, they neither learn about others' similar feelings and experiences nor avail themselves of the opportunity to confide in, and ultimately to be validated and accepted by others. In group dynamics, such as in joining an online support group, especially in the early stages, the disconfirmation of a client's feelings of uniqueness is a powerful source of relief. After hearing other members disclose concerns similar to their own, clients report feeling more in touch with the world and describe the process as a "welcome to the human race" experience. Simply put, the phenomenon finds expression in the cliché "We're all in the same boat"—or perhaps more cynically, "Misery loves company" (Yalom & Leszcz, 2005, p. 6).

This study also affirms the findings of Yao et al. (2015) that relatedness, as a new dimension of online social support satisfies stigmatized patients' needs to connect with others in virtual communities. Meanwhile, the study of Philipps & Rees (2018) emphasizes that conscious involvement in online support groups can somehow offset the negative effects of invisibility. Online peer recognition of individual experiences can create a unique avenue for validation and respect. People whose suffering is hidden exert effort to be involved in visibility work—not just to draw biomedical attention, but also to transform their suffering into one that is recognizable, valid, and accepted socio-politically (Phillips & Rees, 2018, p.27).

The findings of this study also support the assumptions made that interactions with people who share the same experiences are of better help to adults with RA than those who do not; identifying with people who have the same disease fosters inclusivity and belongingness. Through interaction with online support groups, adults with RA learn to espouse other group members' coping techniques and viewpoints.

This work's strengths are a patient-centric and patient-driven discovery that presents a deeper insight into the daily challenges of adults with RA and the process by which an online support group offers to facilitate their coping.

Conclusion

The emergent theoretical model was, essentially, the researcher's interpretation of the constructions of the 15 participants of their experiences and coping. The results of this study are distinct to the researcher, participants, and context of this study as is commonly the case in qualitative research. The transferability of this theoretical model for coping unfolds as the reader evaluates the findings based on the applicability of specific situations to them.

Recommendations

The study presents adults' experiences with RA and the utility of an online support group to their coping. The study sheds light on the often misunderstood course of symptomatology and the struggles the afflicted adults go through. Despite having social media as the milieu by which these concepts emerge, the theoretical model presented in this study might help health practitioners understand adults afflicted with diseases where symptoms are imperceptible. Understanding their experiences in the context of the theoretical model presented could suggest information and support modalities for these groups of people.

Limitations, Researcher Characteristics and Reflexivity

The researcher who has Rheumatoid arthritis too undertook all roles pertinent to the study (interviewer, transcriptionist, and data analyst). The researcher is aware that personal biases contaminating data are unavoidable but may be minimized. The attempts to reduce personal biases included employing a reflexive approach to the analysis, controlling the inquiry and systematizing it, maintaining an objectivist perspective "(Singh & Estefan, 2018), strict adherence to the Straussian's Grounded Theory procedures, and by recording observations and memos immediately after completion of the data collection.

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Acknowledgment

The author would like to express sincere gratitude to Araceli O. Balabagno, Ph.D. of the University of the Philippines Manila, College of Nursing for the tutelage and guidance in the conduct and completion of the grounded theory study, to Rosario Pajarin-Baes, M.D., FPCP for the generosity and consent to access participants, to the administrators and members of the Facebook group Filipinos with Rheumatoid Arthritis for the trust and participation and to Far Eastern University for the encouragement. Appreciation is also given to Susan L. Morrow, Ph.D. (deceased), and Mary Lee Smith, Ph.D. of Arizona State University for the inspiration and generosity.