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## "To be lonely in your own loneliness"

*The interplay between self-perceived loneliness and rheumatoid arthritis in everyday life: A qualitative study*

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**Title “To be lonely in your own loneliness”: The interplay between self-perceived loneliness and rheumatoid arthritis in everyday life: A qualitative study**

**Abstract**

**Objective:** Loneliness has a negative impact on physical health, and rheumatoid arthritis symptoms can lead to social isolation. However, there is a lack of research exploring patients’ perspectives on self-perceived loneliness in everyday life with rheumatoid arthritis. The purpose of this study was to gain insight into the meaning and importance of self-perceived loneliness among adult patients diagnosed with rheumatoid arthritis.

**Methods:** This study was designed as a qualitative, exploratory interview study using a narrative framework. Semi-structured interviews were conducted with Danish adults with rheumatoid arthritis. All interviews were recorded, transcribed verbatim and analyzed within a narrative thematic framework.

**Results:** Ten women and 7 men were interviewed, age between 18 and 73 years and a disease duration between 6 months and 40 years. Three themes emerged during the analysis: 1) explanations of loneliness in everyday life with rheumatoid arthritis, 2) disclosing or disguising loneliness, and 3) feelings of loneliness in social life.

**Conclusion:** The findings from this study show that loneliness can be burdensome when living with RA. Narratives of loneliness can be hard for patients to disclose, so health care practitioners should take responsibility for legitimizing this subject. A narrative approach in consultations may be helpful to support patients and to encourage a dialogue about loneliness in everyday life with rheumatoid arthritis.

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Over the last decade, studies have documented that loneliness poses a serious threat to general health (Cacioppo & Cacioppo, 2014; Holt-Lunstad, 2017). Loneliness is a risk factor for increased blood pressure and cardiovascular diseases (Hawkley, Thisted, Masi, & Cacioppo, 2010; Valtorta, Kanaan, Gilbody, Ronzi, & Hanratty, 2016), and one study among cardiac patients found strong association between loneliness and poor patient reported outcomes as well as one-year mortality (Christensen et al., 2020), although causality is complex and multifactorial and not easily established (Holt-Lunstad & Smith, 2016). Loneliness may impact people with chronic illness in different ways. Apart from the physiological consequences mentioned above, perceptions of loneliness can adversely impact general wellbeing (Ernst & Cacioppo, 1999; Miller, 1985), coping (Lopez-Martinez, Esteve-Zarazaga, & Ramirez-Maestre, 2008), medication management (DiMatteo, 2004; Kusaslan Avci, 2018), and perception of illness and pain (Jaremka et al., 2013; Ozkan Tuncay, Fertelli, & Mollaoglu, 2018; Smith, 2017).

In the literature, loneliness is defined in different ways and within different theoretical frameworks. Weiss (Weiss, 1973) made a distinction between emotional and social loneliness, Peplau and colleagues (Peplau & Perlman, 1982) contributed with nuanced theoretical perspectives in their book on loneliness and lately Rokach and Sha'ked (Sha'ked & Rokach, 2017) contributed with wide-ranging perspectives and coping mechanisms of loneliness.

There is a large amount of research studying loneliness in different population segments. Special attention has been drawn to old and very young population groups (Nikolajsen, Hedelund, & Swane, 2014), and there are several studies on loneliness in people with chronic illness in these specific age groups (Maes et al., 2017; Smith, 2017; Theeke, Mallow, Gianni, Legg, & Glass, 2015). Studies involving adult patients with rheumatoid arthritis (RA) are mainly quantitative, focusing on the prevalence of loneliness and its impact on inflammation, cardio-vascular disease, and mortality

(Benka et al., 2012; El-Mansoury et al., 2008; Kool & Geenen, 2012; Tiwana, Rowland, Fincher, Raza, & Stack, 2015). Living with RA can impact psychological well-being (Ryan, 2014) and constrain social life (Benka et al., 2012; Laidmäe, Leppik, Tulva, & Hääl, 2009; Poh et al., 2017) due to pain, fatigue and disability from the illness. To our knowledge, no studies have included adults with RA to explore self-perceived loneliness and its impact on everyday life.

### **Aim**

This study aims to gain insight into the meaning and importance of self-perceived loneliness among patients diagnosed with rheumatoid arthritis.

In this study, the idea of loneliness as a non-pathological and non-existential phenomenon is embraced: rather, loneliness is viewed as the self-perceived discrepancy between desired relations and actual relations (Peplau & Perlman, 1982). Loneliness is furthermore conceptualized as a subjective experience within the context of the different communities available to the individual (Holt-Lunstad, 2017).

### **Research questions**

- How does loneliness emerge in the everyday lives of people living with rheumatoid arthritis?
- How is loneliness experienced and articulated by people living with rheumatoid arthritis?
- What conditions may modify the experience of loneliness in the everyday lives of people living with rheumatoid arthritis?

## **METHODS**

### **Design**

The study was designed as a qualitative, exploratory interview study using a narrative framework that focuses more on the patients' storytelling and less on the narrative research tradition of structure, frame and temporality described by e.g. Labov (Riessman, 2008) and Czarniawska (Czarniawska, 2004). The narrative approach in this study is rooted in a hermeneutic-phenomenological tradition, where a phenomenon is appreciated as it appears, yet interpreted through the reflections of both narrator and the listener through a semi-structured dialogue (Frank, 2012; Riessman, 2008).

### **Recruitment**

The eligibility criteria for participation in this study were: men and women with a personal perception of being lonely and diagnosed with RA, older than 18 years of age and capable of speaking and understanding Danish. Purposeful sampling (Sandelowski, 1995) was used to achieve diversity in perspectives, age, gender and social background.

The participants were advertised for on Facebook and information on the study was shared in specific groups related to both RA and loneliness. Furthermore, folders with project information were placed in different outpatient rheumatology departments throughout the region of Southern Denmark. Finally, male participants from a previous survey (not yet published) within the department of Rheumatology were invited to participate in the study.

### **Participants**

In total, 17 participants (10 women) with rheumatoid arthritis and self-perceived loneliness were included in the study. Inclusion was terminated when diversity in age, gender and disease duration were reached. Participants were between 18 and 73 years of age (mean: 49 years) and from all areas of Denmark. Their disease duration ranged from 6 months to 40 years (mean: 11 years). See Table 1 for details on recruiting and characteristics of the participants.

## **Interviews**

A semi-structured interview guide was developed based on the existing literature on loneliness and the authors' clinical experiences. Difficulties in recruitment and the delicate subject meant that no patients were directly involved in the development of the interview guide. However, the relevance of the subject was discussed in a public meeting with people with chronic illness. The opening question in the interview guide was: "How is your everyday life with RA – how do you experience loneliness in everyday life?" (Table 2). The interviews were conducted, in accordance with participant's preference, either in a hospital or in their own home (Table 1). One patient had family members present during the interview. The mean duration of interviews was 72 minutes (range 37-160 minutes) and the first author performed the interviews.

All interviews were recorded and transcribed verbatim.

## **Ethics approval and consent to participate**

The study was not registered with the Danish National Committee on Health Research Ethic due to Danish laws regarding research for qualitative studies. It was reported to the Danish Data Protection Agency (2008-58-0035) and is in accordance with the 1964 Helsinki declaration and its later amendments (World Medical Association, 2013) .

All participants completed a consent form after receiving oral and written information. The participants were informed that they could withdraw from the study without any consequences and that their personal details would be unrecognizable in the final article.

## **Analysis**

Data were anonymized by removing names and recognizable data in the final presentation, and participants were identified by ID plus number. Data were analyzed using a thematic narrative

analysis as described by Riessman (Riessman, 2008) and with inspiration from dialogical narrative analysis (Frank, 2012; Salway & Gesink, 2018).

All interviews were read and re-read in the first stage of analysis, with the preliminary analysis focusing on the individual stories of all 17 participants. In the second stage, narrative themes were identified across the participants' interviews (Gibbs, 2018; Riessman, 2008). Thirdly, analysis of the interviews was performed several times by first and last authors, with participants' stories discussed with an open mind, looking for possible themes and synthesis. This was a dialogical, iterative and nonlinear process (Salway & Gesink, 2018) (Table 3).

## RESULTS

The empirical findings prompted an iterative process resulting in the identification of the following three themes related to loneliness in life with RA (Table 3).

### ***Explanations of loneliness in everyday life with RA***

To some of the participants, the inception of loneliness was related to becoming ill with RA. They provided a story of loneliness rooted in physical limitations, fatigue and pain – and for some of the participants the mental stress increased concurrently with the diagnosis and progression of RA. One participant told a story filled with expressions of loneliness, yet she claimed not to be lonely *in general*. Her loneliness was present as a direct consequence of the RA, and she was able to separate disease-specific loneliness from her “normal” self.

I do not consider myself lonely, but maybe I'm lonely in the illness because I choose to hide it and that's it. Well I might be lonely 'in the illness,' as in 'chronically ill.' But I as a person am definitely not lonely. (ID 06)

Physical limitations carried special weight for most of the male participants. They shared stories wherein RA-induced loneliness was connected to their self-understanding of their male identity and to feelings of expectations attached to masculinity and male gender roles. Physical limitations from RA symptoms restricted social participation in certain activities linked to gender identity formation, and this further led to a threat of social exclusion that required coping skills.

So, as a man with arthritis, it's possibly a little bit more...you just have to live with it, right. And be more independent. And I think you get a bit more tough, right.

Well. A bit more: "Oh, but I can just manage on my own", right. (ID 09)

Other participants articulated the experience of loneliness as being exacerbated by RA, but primarily connected to early life events which impacted their social interaction skills, social participation, and feelings of loneliness. One participant reflected upon this and interpreted her feeling of loneliness as a direct effect of being sexually abused in childhood.

It probably has to do with my childhood, because I'm an institutionalized child and have been since I was a baby, and I've moved so many times in my life that I never had any attachment – that is, I know a lot of people, but not anybody that I see in, like, private. (ID 03)

The participants who revealed specific life circumstances from their upbringing, or who claimed that their loneliness was rooted in their personality, regarded loneliness as a determining factor in their life. The RA diagnosis was seen as yet another burden of their intrinsic loneliness, because physical limitations, pain, fatigue and diminished mental strength made it even more difficult to stay in meaningful activities, communities or relations.



...and of course, it's related to my personality, my upbringing and everything, because once you are betrayed, well then you're let down, and there's nothing to do (...) And actually that's the biggest obstacle in my loneliness, I think. (ID 08)

On the contrary, participants who considered loneliness as a direct consequence of living with RA rejected the narrative of personality or childhood factors initiating their feeling of loneliness, even if they had experienced a traumatic upbringing.

That [loneliness] feels like it has just something to do with my illness. [...] Because of this, when I place it inside, it can sometimes be negative because you don't get to ask for help enough [...] but I really can't find that feeling of loneliness in my personality. (ID 07)

Other participants perceived loneliness as a positive experience or even as a contemplative practice that helped them to stay focused or gain a reprieve from everyday life. In this sense, they did not distinguish loneliness from being alone. But although they found positive angles to loneliness, they too reported negative emotions connected to being lonely.

...When I am having a bad time, that I just, am allowed to dwell on it by being myself and to be alone and lonely and to be able to work with the things, I think is difficult for me. So, this, by accepting that I can't do everything! (ID 15)

This explanation demonstrated how stories could help transform loneliness into a positive, meaningful and maybe even necessary experience in living with RA – something that was perhaps also helpful in managing the illness.

### ***Disclosing or disguising loneliness***

Most participants expressed difficulties in explaining what loneliness meant to them in their life with RA, how it emerged, and if/how they managed to be open about it. As one participant explained:

Along the road, then it's me trying to work with that loneliness. And I find it difficult being lonely. And to call it loneliness. Because I bloody don't want to be lonely! You know, it means something to me too, not to be lonely. And to talk about it, to disclose it in some way, right? And actually, this is probably the worst part of being lonely and what keeps you in loneliness, I suppose. (ID 08)

Similarly, all participants spoke about the difficulty of revealing their loneliness, and it became clear that loneliness was not something one discussed openly with friends, colleagues or family members. One participant mentioned that loneliness was taboo, and other participants confirmed this, though without explicitly naming it: "Well yes, it's hard to share this about being lonely because it's like...a taboo area" (ID 07).

The trouble with expressing loneliness also became clear when some participants articulated that they had not revealed their experience of loneliness to even their closest confidantes. One male participant found that sharing the experience of loneliness with his partner was much harder than sharing suicidal thoughts.

Some participants reasoned that they could have or should have been more active in preventing exclusion and loneliness in order to become a more active part of society. They expressed feelings of guilt and resignation with regard to their future activities and responsibilities in preventing loneliness.

(...) So it usually ends up with that I actually am alone and think "Okay, will it ever change, will I ever work again (...) why don't I just go to see someone that I can

talk to?" So I do feel alone sometimes, it is self-inflicted when you don't get out, but I just think it's hard, it's very hard. Yes, I feel alone many many many times, I do. (ID 11)

Some participants stated a wish for the health care practitioners to listen to their stories of loneliness and maybe to offer counselling and advice. On the other hand, they felt it was difficult to share these stories, since their relationship with the health care professionals was considered too superficial to share existential problems. Many participants reported that the most important thing in a clinical consultation was to be listened to, whereas specific solutions were less important.

### ***Feelings of loneliness in social life***

A large portion of the participants shared stories about feeling excluded from societies or from social activities as part of their experience of loneliness. The restricted access to social life was based on both physical restraints and a lack of mental energy, and for most of the participants these limitations were viewed as consequences of their RA.

Many participants expressed that employment helped them to establish an identity, where recognition and value of the individual was essential. When the illness led to physical limitations, sick leave or unemployment, the consequences were withdrawal from social contact or an experience of social exclusion. Thoughts related to the future, the job situation and the family were difficult to share with others, because most of the participants had encountered a lack of understanding from others: their identity and sense of self became related to shame, stigma or social exclusion.

Yes, but I do tell my friends now and again that I feel lonely, really. They can sort of go to work. And have social relations. If I want to create any contacts...well then

I have to do something myself, and that's the case every single day. I really miss being in the job market, right. (ID 07)

Many participants shared their thoughts on the possible future development of their RA, and some mentioned a fear of worsening disabilities, aging, and feeling even more lonely. The connection between old age and experiencing loneliness was mentioned by almost all 17 participants. The risk of being exposed to a kind of double loneliness, that of being left alone and losing your partner, thus losing one's sense of self and not being able to participate in everyday life, was seen as a scary negative spiral that most participants had reflected upon: "...when you're withdrawing, you're lonely in your own loneliness. Because you don't get out to make those social relations, so I probably become more and more of a loner on account of that" (ID 07).

Most participants had constructive intentions to reduce their loneliness, but it was obvious that it was often hard work to implement these intentions in their everyday life.

(...) Then when you sit there, feel sad and have the feeling that you don't have anybody, even though you know that you could just text or phone or do something, but you're sitting all alone. You just don't take the next step to get over it. Then you feel very alone. (ID 01)

The need for strategies to prevent or dissolve the feelings of loneliness was expressed in different ways by the participants. Feelings of hopelessness and emptiness were articulated when participants were asked about their future strategies for handling loneliness.

## **DISCUSSION**

The findings from this study contribute to the understanding of how loneliness is perceived and expressed as a very complex and opposite phenomenon of both positive and negative significance

in everyday life with a chronic illness such as rheumatoid arthritis. The study revealed a relation between experiences in early life and loneliness for some participants, who used these experiences to explain their feelings of loneliness and how their personality had developed. Similar findings were presented in a Danish qualitative study (Nikolajsen et al., 2014), where experiences of loneliness in the adult general population were connected to childhood and upbringing.

However, in this study it was found that other perceptions of loneliness were just as important as issues from one's childhood and upbringing. These included the inception of loneliness related to RA diagnosis and living with the symptoms of the illness.

Most of the participants were living with a partner and both young, middle-aged and older adults were included (Table 1). This diversity of all participants points to the presence of loneliness at individuals of all ages and in all stages of illness, and within a broad spectrum of patient characteristics, and accentuate that marriage and middle age do not necessarily mitigate the experience of loneliness.

An epidemiological study from Denmark (Lasgaard, Friis, & Shevlin, 2016) and similar results from England (Holt-Lunstad, Smith, & Layton, 2010) present loneliness as more prevalent in the younger and older age groups and among unemployed and unmarried persons in the general population, but findings from the present study show the nuanced and heterogenous characteristics of how loneliness presents in the everyday lives of people with RA.

The complexity in these findings can be attributed to Spiers' perspectives of vulnerability as both emic and etic (Spiers, 2000), where emic is defined as the subjective individual experience of a specific concept, and etic is defined as the objective external assessment of this concept, including possible risks.

Participants' experiences of loneliness were found to be complex, including etic factors as being diagnosed with RA and with a certain upbringing, and emic factors including feelings of shame but also more positive reflections about loneliness.

Using narratives of loneliness provided a better way to understand patients' experience of vulnerability, and emphasizes that it is not sufficient to examine solely the objective demographic or biomedical factors related to vulnerability, loneliness or possible suffering. The findings support that patient narratives can be an important part of the encounter between the patient and the health care provider, since the individual experience affects how loneliness is perceived, handled and presented to the listener – and how it affects everyday life with RA.

At the same time, research suggests that the individual story tends to be neglected during the encounter with the health-care system for different reasons. Kvirgic et al. (Kvirgic, Asiedu, Crowson, Ridgeway, & Davis, 2018) and Dures et al. (Dures et al., 2017) both find poor communication in the patient-health care professional encounter in rheumatology, leading to patients feeling unheard and discordance between how the patient presents symptoms and how the health care provider interprets them. This is supported by the findings in the present study, since the participants emphasize personal, trusting relations within the health system and the importance of an individual experience focus.

An additional emotion that clearly emerged from the data was the concept of guilt. Blaming one's self for loneliness and not being able to solve one's social exclusion renders the loneliness even harder to share. The findings show that the disclosure of loneliness was much harder than the disclosure of other vulnerable stories from the participants' lives. Nikolajsen et al. (Nikolajsen et al., 2014) present a similar case of loneliness as taboo in the general population, and found that taboo stemmed from two factors: stigma from surroundings due to not meeting expectations for a

“normal” active social life, and insecurity from surroundings in how to talk to people experiencing loneliness.

The participants in this study were trying to make sense and meaningfulness out of their stories by explaining the origin of their loneliness and reflecting upon why they were unable to articulate thoughts about loneliness. Their explanations pointed to personality, upbringing and RA-specific factors that contributed to their current feeling of loneliness.

Frank’s “dramas of illness” (Frank, 2007) supports findings from the present study with its analysis of chronic illness in everyday life and the meaning of narratives shaping perceptions of illness.

Frank states that narratives promote understanding in the encounter between patients and health care practitioners (Frank, 2007).

The drama of emotions surrounding loneliness in life with RA is present in the participants’ feelings of guilt and shame. In this drama, negative emotions must be kept from the people closest to the ill person (Frank, 2007), and therefore feelings of loneliness along with the emotions of guilt and shame cannot be disclosed to family or friends, since they will only cause more sorrow and frustration. In this predicament, health care practitioners may again be of help in listening to the patients’ individual stories. In the process of arriving at a meaningful story, health care professionals are responsible for witnessing these stories and providing help as necessary (Frank, 2007). This notion is supported by Charon (Charon, 2001), who talks about “bearing witness” to patients’ stories and reminds us that special competencies are required in narrative medicine to be aware of this (Charon, 2006).

The “drama of meaning” was generated during analysis in the data throughout the dialogue between the participants and the researcher. Through this reflective practice, the participants became aware of new perspectives on loneliness in everyday life with RA. This highlights the need

for a narrative dialogue in the encounter between patient and health care practitioner as suggested by Frank (Frank, 2007) and Charon (Charon, 2006). Charon claims that the attention to patients' narratives in health care provides "opportunities for respectful, empathetic and nourishing medical care" (Charon, 2001).

The participants in this study expressed fear of losing their physical abilities due to RA, including loss of employment and the capacity to participate in social events. The "drama of fear and loss" is in this sense about fear and loss connected to the participants' chronic illness and to the physical or mental loss that can induce fear about future loneliness. This loss is somehow connected to the "drama of self," since there is always identity work connected to being ill: the fear of losing important life dimensions and the possible need to develop a new self, a re-negotiated identity. In the narratives of loneliness in this study, tension exists between the participants admitting their own loneliness and trying to maintain a facade for their surroundings. These findings accentuate the need to address loneliness in health care consultations, since patients are seeking continuous relations with health care providers in order to share their illness narratives.

The study had some limitations. The sampling strategy may have led to a selected group of participants who were active on social media and who had the time, interest, willingness and energy to share their personal stories of loneliness. Many participants mentioned that they were recovering from a difficult time with their RA, being in a more stable period when the interview took place.

Selection bias may hamper the representativity of this study. Arguably, however, the insights gained from these interviews are potentially useful and can be transferable to other encounters with patients in rheumatology.



In summary, the findings from this study show that loneliness can be a burden in everyday life with RA and therefore an important topic to address in encounters with the patient. The findings support the notion that minimizing taboo and stigma surrounding loneliness may relieve the burden from the individual; more focus on narrative medicine is needed to better understand these patients.

The narrative of loneliness can vary from one individual to another, which implies that every patient must be met with an open, curious and individualized approach. The participants largely agreed that health care practitioners may well address loneliness – but it requires a trusting relationship, and it is up to the health care practitioner to establish such a relation. Thus, health care professionals need to have communicative skills and competency to handle and acknowledge patients' personal narratives and to reduce social isolation, thereby reducing loneliness experienced by the patient.

## References

- Benka, J., Nagyova, I., Rosenberger, J., Calfova, A., Macejova, Z., Middel, B., . . . Groothoff, J. W. (2012). Social support and psychological distress in rheumatoid arthritis: a 4-year prospective study. *Disabil Rehabil*, *34*(9), 754-761. doi:10.3109/09638288.2011.619618
- Cacioppo, J. T., & Cacioppo, S. (2014). Social Relationships and Health: The Toxic Effects of Perceived Social Isolation. *Soc Personal Psychol Compass*, *8*(2), 58-72. doi:10.1111/spc3.12087
- Charon, R. (2001). The patient-physician relationship. Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA*, *286*(15), 1897-1902. doi:10.1001/jama.286.15.1897
- Charon, R. (2006). *Narrative medicine: honoring the stories of illness*. Oxford New York: Oxford University Press.
- Christensen, A. V., Juel, K., Ekholm, O., Thrysoe, L., Thorup, C. B., Borregaard, B., . . . Berg, S. K. (2020). Significantly increased risk of all-cause mortality among cardiac patients feeling lonely. *Heart*, *106*(2), 140-146. doi:10.1136/heartjnl-2019-315460
- Czarniawska, B. (2004). *Narratives in Social Science Research*. London.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychol*, *23*(2), 207-218. doi:10.1037/0278-6133.23.2.207
- Dures, E., Fraser, I., Almeida, C., Peterson, A., Caesley, J., Pollock, J., . . . Hewlett, S. (2017). Patients' Perspectives on the Psychological Impact of Inflammatory Arthritis and Meeting the Associated Support Needs: Open-Ended Responses in a Multi-Centre Survey. *Musculoskeletal Care*, *15*(3), 175-185. doi:10.1002/msc.1159
- El-Mansoury, T. M., Taal, E., Abdel-Nasser, A. M., Riemsma, R. P., Mahfouz, R., Mahmoud, J. A., . . . Rasker, J. J. (2008). Loneliness among women with rheumatoid arthritis: a cross-cultural study in the Netherlands and Egypt. *Clin Rheumatol*, *27*(9), 1109-1118. doi:10.1007/s10067-008-0876-2
- Ernst, J. M., & Cacioppo, J. T. (1999). Lonely hearts: Psychological perspectives on loneliness. *Applied and Preventive Psychology*, *8*(1), 1-22. doi:10.1016/s0962-1849(99)80008-0
- Frank, A. W. (2007). Five dramas of illness. *Perspect Biol Med*, *50*(3), 379-394. doi:10.1353/pbm.2007.0027
- Frank, A. W. (2012). Practicing Dialogical Narrative Analysis. In *Varieties of Narrative Analysis* (pp. 33-52). Thousand Oaks, California: Holstein and Gubrien.
- Gibbs, G. (2018). Analyzing Biographies and Narratives. In *Analyzing qualitative data* (2 ed., pp. 210 p, illustreret). Los Angeles: SAGE.
- Hawkey, L. C., Thisted, R. A., Masi, C. M., & Cacioppo, J. T. (2010). Loneliness predicts increased blood pressure: 5-year cross-lagged analyses in middle-aged and older adults. *Psychol Aging*, *25*(1), 132-141. doi:10.1037/a0017805
- Holt-Lunstad, J. (2017). The Potential Public Health Relevance of Social Isolation and Loneliness: Prevalence, Epidemiology, and Risk Factors. *Public Policy & Aging Report*, *27*(4), 127-130. doi:10.1093/ppar/prx030
- Holt-Lunstad, J., & Smith, T. B. (2016). Loneliness and social isolation as risk factors for CVD: implications for evidence-based patient care and scientific inquiry. *Heart*, *102*(13), 987-989. doi:10.1136/heartjnl-2015-309242
- Holt-Lunstad, J., Smith, T. B., & Layton, J. B. (2010). Social relationships and mortality risk: a meta-analytic review. *PLoS Med*, *7*(7), e1000316. doi:10.1371/journal.pmed.1000316
- Jaremka, L. M., Fagundes, C. P., Glaser, R., Bennett, J. M., Malarkey, W. B., & Kiecolt-Glaser, J. K. (2013). Loneliness predicts pain, depression, and fatigue: understanding the role of immune dysregulation. *Psychoneuroendocrinology*, *38*(8), 1310-1317. doi:10.1016/j.psyneuen.2012.11.016
- Kool, M. B., & Geenen, R. (2012). Loneliness in patients with rheumatic diseases: the significance of invalidation and lack of social support. *J Psychol*, *146*(1-2), 229-241. doi:10.1080/00223980.2011.606434

- Kusasan Avci, D. (2018). Evaluation of the relationship between loneliness and medication adherence in patients with diabetes mellitus: A cross-sectional study. *J Int Med Res*, 46(8), 3149-3161. doi:10.1177/0300060518773223
- Kvrgic, Z., Asiedu, G. B., Crowson, C. S., Ridgeway, J. L., & Davis, J. M., 3rd. (2018). "Like No One Is Listening to Me": A Qualitative Study of Patient-Provider Discordance Between Global Assessments of Disease Activity in Rheumatoid Arthritis. *Arthritis Care Res (Hoboken)*, 70(10), 1439-1447. doi:10.1002/acr.23501
- Laidmäe, V.-I., Leppik, L., Tulva, T., & Hääl, M.-L. (2009). Disease-related social and family life: people coping with rheumatoid arthritis in Estonia. *Critical Public Health*, 19(1), 87-105. doi:10.1080/09581590802375871
- Lasgaard, M., Friis, K., & Shevlin, M. (2016). "Where are all the lonely people?" A population-based study of high-risk groups across the life span. *Soc Psychiatry Psychiatr Epidemiol*, 51(10), 1373-1384. doi:10.1007/s00127-016-1279-3
- Lopez-Martinez, A. E., Esteve-Zarazaga, R., & Ramirez-Maestre, C. (2008). Perceived social support and coping responses are independent variables explaining pain adjustment among chronic pain patients. *J Pain*, 9(4), 373-379. doi:10.1016/j.jpain.2007.12.002
- Maes, M., Van den Noortgate, W., Fustolo-Gunnink, S. F., Rassart, J., Luyckx, K., & Goossens, L. (2017). Loneliness in Children and Adolescents With Chronic Physical Conditions: A Meta-Analysis. *J Pediatr Psychol*, 42(6), 622-635. doi:10.1093/jpepsy/jsx046
- Miller, J. F. (1985). Assessment of loneliness and spiritual well-being in chronically ill and healthy adults. *J Prof Nurs*, 1(2), 79-85. doi:10.1016/s8755-7223(85)80010-7
- Nikolajsen, A., Hedelund, M., & Swane, C. E. (2014). "Palle alene i Verden" - et kvalitativt studie af voksnes ensomhed midt i livet ["All alone in the world"]. Retrieved from <https://www.egv.dk/en/funded-projects/327-all-alone-in-the-world-a-qualitative-study-of-loneliness-among-younger-adults>
- Ozkan Tuncay, F., Fertelli, T., & Mollaoglu, M. (2018). Effects of loneliness on illness perception in persons with a chronic disease. *J Clin Nurs*, 27(7-8), e1494-e1500. doi:10.1111/jocn.14273
- Peplau, L. A., & Perlman, D. (1982). *Loneliness : a sourcebook of current theory, research and therapy*. New York: Wiley.
- Poh, L. W., He, H. G., Chan, W. C. S., Lee, C. S. C., Lahiri, M., Mak, A., & Cheung, P. P. (2017). Experiences of Patients With Rheumatoid Arthritis: A Qualitative Study. *Clin Nurs Res*, 26(3), 373-393. doi:10.1177/1054773816629897
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Los Angeles, Calif.: SAGE.
- Ryan, S. (2014). Psychological effects of living with rheumatoid arthritis. *Nursing Standard*, 29(13), 52-59. doi:10.7748/ns.29.13.52.e9484
- Salway, T., & Gesink, D. (2018). Constructing and Expanding Suicide Narratives From Gay Men. *Qual Health Res*, 28(11), 1788-1801. doi:10.1177/1049732318782432
- Sandelowski, M. (1995). Sample size in qualitative research. *Res Nurs Health*, 18(2), 179-183. doi:10.1002/nur.4770180211
- Sha'ked, A., & Rokach, A. (2017). *Addressing Loneliness. Coping, Prevention and Clinical Interventions*: Psychology Press.
- Smith, T. (2017). "On their own": social isolation, loneliness and chronic musculoskeletal pain in older adults. *Quality in Ageing and Older Adults*, 18(2), 87-92. doi:10.1108/qaoa-03-2017-0010
- Spiers, J. (2000). New perspectives on vulnerability using emic and etic approaches. *J Adv Nurs*, 31(3), 715-721. doi:10.1046/j.1365-2648.2000.01328.x
- Theeke, L. A., Mallow, J., Gianni, C., Legg, K., & Glass, C. (2015). The Experience of Older Women Living with Loneliness and Chronic Conditions in Appalachia. *Rural Ment Health*, 39(2), 61-72. doi:10.1037/rmh0000029
- Tiwana, R., Rowland, J., Fincher, M., Raza, K., & Stack, R. J. (2015). Social interactions at the onset of rheumatoid arthritis and their influence on help-seeking behaviour: A qualitative exploration. *British Journal of Health Psychology*, 20(3), 648-661. doi:10.1111/bjhp.12134

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- Valtorta, N. K., Kanaan, M., Gilbody, S., Ronzi, S., & Hanratty, B. (2016). Loneliness and social isolation as risk factors for coronary heart disease and stroke: systematic review and meta-analysis of longitudinal observational studies. *Heart*, *102*(13), 1009-1016. doi:10.1136/heartjnl-2015-308790
- Weiss, R. S. (1973). *Loneliness : The experience of emotional and social isolation*. Cambridge, Mass., The MIT Press.
- World Medical Association. (2013). WMA declaration of Helsinki: Ethical principles for medical research involving human subjects. (Publication no. 10.1001/jama.2013.281053). (0098-7484). <http://www.wma.net/en/30publications/10policies/b3/>

**Table 1. Participant characteristics, setting of interview and method of inclusion**

<b>ID</b>	<b>Gender</b>	<b>Age</b>	<b>Living alone</b>	<b>Illness duration</b>	<b>Setting</b>	<b>Inclusion</b>
01	F	25 years	No	6 months	Face to face, Hospital	Advertisement in the outpatient department
02	F	46 years	No	21 years	Face to face, Home	Facebook
03	F	55 years	No	3 years	Face to Face, Hospital	Facebook
04	F	18 years	No	1 years	Face to face, Home	Facebook
05	F	58 years	No	8 years	Face to face, Home	Facebook
06	F	50 years	No	6 years	Face to face, Home	Facebook
07	F	56 years	No	20 years	Face to face, Home	Facebook
08	F	53 years	No	6 years	Face to face, Home	Facebook
09	M	66 years	No	9 months	Face to face, Hospital	Facebook
10	M	30 years	Yes	2 years	Face to face, Hospital	Consultation/email
11	M	48 years	No	6 years	Face to face, Hospital	Consultation/email
12	M	56 years	No	24 years	Face to face, Hospital	Email
13	M	57 years	No	3 years	Face to face, Hospital	Email
14	M	62 years	No	43 years	Face to face, Home	Email
15	F	51 years	No	2 years	Phone	Facebook
16	M	73 years	No	40 years	Face to face, Home	Email
17	F	29 years	Yes	2 years	Face to face, Hospital	Facebook

**Table 2. Interview guide. Rheumatoid arthritis and loneliness**

<p><b>Introduction:</b></p>	<ul style="list-style-type: none"> <li>• Can you tell me a little bit about yourself – what would you like to tell me about yourself?</li> <li>• Why did you decide to participate in this study?</li> </ul>
<p><b>Living with rheumatoid arthritis:</b></p>	<ul style="list-style-type: none"> <li>• Can you tell me about your everyday life with rheumatoid arthritis?</li> <li>• How would you describe your social life?</li> <li>• What activities do you do in your everyday life? Are there some things you would like to do but are not capable of doing because of rheumatoid arthritis?</li> <li>• Did your life change after the diagnosis? Work – social relations – relationship – mood – activities?</li> <li>• How do you remember your time together with other people before you were diagnosed with rheumatoid arthritis?</li> <li>• Did people change in their behavior towards you after your diagnosis of rheumatoid arthritis?</li> <li>• Who are your closest relatives and friends?</li> <li>• How often do you see them?</li> </ul>
<p><b>Loneliness:</b></p>	<ul style="list-style-type: none"> <li>• (How) do you experience loneliness in your everyday life?</li> <li>• How do you experience loneliness in relation to your illness?</li> <li>• Can you tell me more about what loneliness is to you – would you call it loneliness yourself?</li> <li>• Do you have good days and bad days?</li> <li>• How does loneliness affect your activities and social relations?</li> <li>• Do you feel lonely in a crowd/with other people?             <ul style="list-style-type: none"> <li>○ Can you tell me more about this experience?</li> </ul> </li> <li>• Can you talk to anybody about your loneliness?             <ul style="list-style-type: none"> <li>○ How do you talk to others about loneliness? How do you describe it/which words are you using?</li> </ul> </li> </ul> <p>(If relevant: Do you experience days where you feel unable to live/lack of desire to live? If yes, ask: how often do you think about it? Do you have specific considerations of how to commit suicide?)</p>
<p><b>The encounter with the health care system:</b></p>	<ul style="list-style-type: none"> <li>• Did any health professionals ask you about your social relations/network or family?</li> <li>• Did you ever talk to any health care professionals about your loneliness?</li> <li>• Would you like the health care professionals to ask you about your social life/loneliness?</li> <li>• How would you prefer the health care professionals to address these issues?</li> </ul>
<p><b>Thoughts about the future:</b></p>	<ul style="list-style-type: none"> <li>• If anything was possible, what would you wish for?</li> <li>• Is there something you can do to change your situation?</li> </ul>

**Table 3.** Thematic narrative analysis as described by Riessman and with inspiration from dialogical narrative analysis, an iterative non-linear process

Analysis			Discussion
<p><b>Step 1: Read and reread, focus on the individual story- What is this story about?</b></p> <p>These quotes are examples from the rich and detailed empirical material.</p>	<p><b>Step 2: Narratives across interviews, preliminary themes</b></p>	<p><b>Step 3: Pre-liminary analysis on three occasions, synthesis. Final three themes</b></p>	<p><b>Step 4: Revisiting the material/empirical findings with Franks' five illness dramas (Genesis, Emotion work, Fear and Loss, Self, Meaning)</b></p>
<p><i>"...and of course, it is related to my personality, my upbringing and everything, because once you are betrayed, well then you are let down, and there is nothing to do (...) And actually, that is the biggest obstacle in my loneliness, I think." (ID 08)</i></p> <p><i>"That [loneliness] feels like it has just something to do with my illness. [...] Because of this, I place it inside, it can sometimes be negative because you don't get to ask for help enough [...] I really can't find that feeling of loneliness in my personality." (ID 07)</i></p>	<p>The narratives that came to our attention in this step of the analysis were stories of emotions connected to both the story of loneliness in relation to upbringing and previous life events, and the story of loneliness related to becoming ill with RA, e.g. the physical changes and limitations.</p>	<p><b>Theme 1:</b></p> <p><b>Explanations of loneliness in everyday life with RA</b></p>	<p><b>Genesis</b> <b>Emotion work</b> <b>Meaning</b></p>

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<p><i>“Along the road, then it’s me trying to work with that loneliness. And I find it difficult being lonely. And to call it loneliness. Because I bloody don’t want to be lonely! You know, it means something to me too, not to be lonely. And to talk about it, to disclose it in some way, right? And actually this is probably the worst of being lonely and what keeps you in loneliness, I suppose.” (ID 08)</i></p>	<p>The narratives unfolded by the participants revealed feelings of shame and guilt related to feeling lonely and living with RA. Thoughts of revealing loneliness led to distress, but so did hiding the experience of loneliness – both left the participants vulnerable towards surroundings, family and their own identity work.</p>	<p><b>Theme 2:</b></p> <p><b>Disclosing or disguising loneliness</b></p>	<p><b>Fear and loss</b> <b>Emotion work</b> <b>Self</b></p>
<p><i>“(…) then when you sit there, feel sad and have the feeling of, that you don’t have anybody, even though you know that you could just write [text] or phone or do something, but that one – you’re sitting all alone. You just don’t take the next step to get over it. Then you feel very alone.” (ID 01)</i></p>	<p>Participants’ narratives about loneliness included the strain in both participating and feeling excluded from social activities, and not being part of community. This led to changes in identity and a need for strategies for handling loneliness in (future) life with RA.</p>	<p><b>Theme 3:</b></p> <p><b>Feelings of loneliness in social life</b></p>	<p><b>Emotion work</b> <b>Self</b> <b>Fear and loss</b> <b>Meaning</b></p>