Embeddings were generated using all-MiniLM-L6-v2. Dimensionality reduction was performed with UMAP (n\_neighbors = 10, n\_components = 2, min\_dist = 0.1, cosine metric), followed by clustering with HDBSCAN (min\_cluster\_size = 50, euclidean metric, EOM selection). The minimum cluster size was chosen to balance coherence and granularity in a dataset of this scale. A CountVectorizer with English stopwords (min\_df = 2, ngram\_range = 1–4) captured frequent and multi-word pain phrases.

Topic modeling details, Representative Docs

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Topic | Count | Name | Representation | Representative\_Docs |
| -1 | 5009 | -1\_pain\_joint\_iâ\_joint pain | ['pain', 'joint', 'iâ', 'joint pain', 'like', 've', 'just', 'fatigue', 'painful', 'hurts'] | ['the pain. is.', 'i am in so much pain and all i can do is cry.', 'joint pain would move around.'] |
| 0 | 1665 | 0\_lupus\_arthritis\_rheumatoid\_rheumatoid arthritis | ['lupus', 'arthritis', 'rheumatoid', 'rheumatoid arthritis', 'rheumatologist', 'diagnosed', 'symptoms', 'ana', 'joint', 'pain'] | ["yesterday we went to the rheumatologist and turns out the blood test show that it's either lupus or rheumatoid arthritis.", 'i have rheumatoid arthritis.', 'Today I had my appointment with a new rheumatologist as I had moved and she re diagnosed me with Lupus and psoriatic arthritis.'] |
| 1 | 1297 | 1\_pain\_just\_feel\_day | ['pain', 'just', 'feel', 'day', 'life', 'like', 'pain pain', 'time', 'walk', 'don'] | ['and i see all of you and your pain.', 'is this survivable or am i doomed to be in pain after this?', 'i already have pain everywhere.'] |
| 2 | 1247 | 2\_rash\_fatigue\_symptoms\_fog | ['rash', 'fatigue', 'symptoms', 'fog', 'brain fog', 'brain', 'joint', 'fever', 'rashes', 'mouth'] | ['I have many physical symptoms like the face rash, joint pain/swelling, unintentional weight loss, hair loss/thinning, extreme fatigue and brain fog.', 'the symptoms i have are (extreme horrible fatigue, muscle and leg weakness, hives, butterfly rash, sun rashes and sensitivity, breathing chest pains and out of breath symptoms, mouth ulcers, headaches and joint pains, low grade fevers, brain fog, and my fingers get easily freezing now but have not showed the symptom of turning white and also more symptoms!)', 'I have had low grade fevers every day 99.6-100 for 1 month along with lower abdominal discomfort, nausea, extreme fatigue, gritty eyes, butterfly rash(comes and goes), severe joint pain (particularly the hands and feet), over all weakness, rashes sometimes itchy, mouth sores, dry mouth, constipation, weight loss, gassiness.'] |
| 3 | 607 | 3\_joint\_joint pain\_joints\_pain | ['joint', 'joint pain', 'joints', 'pain', 'knees', 'knee', 'hands', 've', 'pain joint', 'years'] | ['i have some joint pain', 'but the joint pain.', 'i still had joint pain'] |
| 4 | 495 | 4\_pain\_told\_arthritis\_help | ['pain', 'told', 'arthritis', 'help', 'said', 'lupus', 'just', 'symptoms', 'pains', 'joint'] | ['and she is in pain.', 'she was in so much pain.', 'so, here is a list of everything that is an issue for her: positive ana homogenous (very high), positive ana speckled (borderline), horrible chronic fatigue, horrible chronic pain in muscles, joints, and ligaments, ibs/crohns markers were very high, mood swings, depression, awful anxiety, excessive sleeping (10-14 hours and is never well rested), heat rashes, no tolerance to cold, raynauds in her fingers where she says it feels like her fingers are on fire after being in the cold and turn very pale and somewhat bluish, general numbness and tingling in her hands and feet, very bad muscle stiffness, no immune system, very dark urine all of the time, literally no medications help with the pain (gabapentin helps relieve probably a quarter of it and is the only thing that helps with pain in any significant way), nsaids and steroids do not help at all, very sensitive to light (eyes), bloated often (eats a fairly healthy diet and avoid sodas and sugars), concentration and memory problems, chest pains, tachycardia (her rest rate is around 100-110 bpm and sleeping it stays around 80 bpm),constant low grade fever, around 99 to 100, and recently started having constant diarrhea (4 or 5 times a day), severe heartburn to the point she pukes, and severe nasuea.'] |
| 5 | 489 | 5\_chest\_chest pain\_breath\_heart | ['chest', 'chest pain', 'breath', 'heart', 'chest pains', 'breathing', 'pain', 'pains', 'breathe', 'deep'] | ['i woke up with chest pain', 'do any of you have chest pain?', 'chest pain?'] |
| 6 | 451 | 6\_headaches\_headache\_neck\_migraine | ['headaches', 'headache', 'neck', 'migraine', 'migraines', 'head', 'day', 've', 'neck pain', 'tension'] | ['headaches.', 'headaches.', 'he always has headaches.'] |
| 7 | 283 | 7\_stomach\_abdominal\_abdominal pain\_stomach pain | ['stomach', 'abdominal', 'abdominal pain', 'stomach pain', 'nausea', 'diarrhea', 'abdomen', 'gas', 'bloating', 'cramps'] | ['it started with unexplained abdominal pain.', 'i had no stomach pain.', 'recently, i seem to have stomach pain/diarrhea almost every other day.'] |
| 8 | 261 | 8\_meds\_tylenol\_pain meds\_ibuprofen | ['meds', 'tylenol', 'pain meds', 'ibuprofen', 'pain', 'killers', 'pain killers', 'taking', 'otc', 'relief'] | ['my normal pain meds (aleve, tylenol, etc), seem to have no effect.', 'no pain meds needed.', 'i have pain meds.'] |
| 9 | 250 | 9\_flare\_flares\_ups\_flare ups | ['flare', 'flares', 'ups', 'flare ups', 'joint', 'joint pain', 'pain', 'iâ', 'fatigue', 'bad flare'] | ['my past flare ups were all joint pain and swelling.', "i think this is why i am hesitant to start the medication, because i feel like i need to see the results on paper, before i can come to terms with needing this treatment.\n\nto add additional context, here are my symptoms:\n\n-cognitive disfunction (decline in reading comprehension/word recall/confusion etc)\n-fatigue (which is debilitating during a bad flare)\n-head to toe pain (this is a constant low level pain until a flare comes, then it jumps up in intensity)\n-hair loss (the all over kind of hair loss..forgot what that's called but it's getting very thin all over and constantly falls out everywhere)\n-peripheral neuropathy (arms/legs/hands/feet/face all effected)\n-balance and gait issues \n-exercise intolerance (during flares)\n-swelling (noticeably puffy face and hands)\n-fevers (these only go up between 99.1 - 99.5 and only occur during bad flare-ups / they also seem worse in the evening)\n-muscle loss (can no longer get injections in arms)", 'the pains happen regardless of flare or no flare.'] |
| 10 | 222 | 10\_hand\_hands\_fingers\_wrist | ['hand', 'hands', 'fingers', 'wrist', 'wrists', 'hand pain', 'swollen', 'thumb', 'feet', 'ache'] | ['does anyone else have trouble w hand pain?', 'i have joint swelling/pain throughout my body my right hand/wrist has been swollen and redder than my other hand for over 3 months.', 'i literally have had my right hand red and swollen for over 3 months with pain in my whole hand that varies and moves day to day between my finger joints/wrist/hand.'] |
| 11 | 206 | 11\_sleep\_night\_morning\_wake | ['sleep', 'night', 'morning', 'wake', 'sleeping', 'pain', 'lay', 'sleep pain', 'woke', 'night pain'] | ['i canâ€™t sleep at night the pain is so disruptive.', "now i can't fall back sleep because of the pain.", 'i canâ€™t sleep some night because of the pain.'] |
| 12 | 186 | 12\_iâ\_iâ pain\_pain iâ\_iâ ve | ['iâ', 'iâ pain', 'pain iâ', 'iâ ve', 'itâ', 'iâ pain iâ', 've', 'pain', 'just', 'pain iâ ve'] | ['iâ€™m always in pain, always.', 'iâ€™m in so much pain.', 'iâ€™m in so much pain ):'] |
| 13 | 179 | 13\_joint\_joint pain\_help\_pain | ['joint', 'joint pain', 'help', 'pain', 'helped', 'help joint', 'arthritis', 'taking', 'fatigue', 'symptoms'] | ['Hi, is anyone here taking any supplements for joint pain?', 'trying to figure out what supplements i can take that will help with joint pain.', 'do you find that braces help with joint pain?'] |
| 14 | 168 | 14\_kidney\_kidneys\_kidney pain\_urine | ['kidney', 'kidneys', 'kidney pain', 'urine', 'bladder', 'protein', 'pain kidneys', 'pain', 'pee', 'pain kidney'] | ['For the past 4 years Iâ€™ve had bad kidney pain that no doctor can explain, I never have an infection and since I have IC my urine always has blood and protein in it so they wonâ€™t attribute that to anything with my kidney function and my blood tests often have high protein and bilirubin but they always determ my kidney is functioning fine.', 'Then, it was kidney pain because of a kidney stone (not sure if it was related and if this drug is hard on kidneys).', 'For the past 4 years Iâ€™ve had bad kidney pain that no doctor can explain, I never have an infection and since I have IC my urine always has blood and protein in it so they wonâ€™t attribute that to anything with my kidney function and my blood tests often have high protein and bilirubin but they always determ my kidney is functioning fine.'] |
| 15 | 157 | 15\_prednisone\_pain\_taking\_mg | ['prednisone', 'pain', 'taking', 'mg', 'dose', 'taper', 'dose prednisone', 'day', 'joint pain', 'joint'] | ['i am on benlysta and prednisone and norco for pain.', 'i just had to take some prednisone for the pain.', "i'm only on prednisone and still in pain."] |
| 16 | 129 | 16\_tips\_pain management\_management\_relief | ['tips', 'pain management', 'management', 'relief', 'pain relief', 'help', 'pain', 'suggestions', 'advice', 'pain tips'] | ['pain management?', 'any tips for pain management?', 'does anyone have any pain management tips for this?'] |
| 17 | 127 | 17\_lower\_lower pain\_spine\_pain | ['lower', 'lower pain', 'spine', 'pain', 'hurts', 'bad', 've', 'upper', 'iâ', 'bad pain'] | ['i do have lower back pain but iâ€™ve had mris in the past which were negative for anything that could explain this.', "i've always had a tender back, and have always had mild lower back pain.", "It's not lower back pain; there's a difference."] |
| 18 | 125 | 18\_plaquenil\_taking plaquenil\_started plaquenil\_taking | ['plaquenil', 'taking plaquenil', 'started plaquenil', 'taking', 'iâ', 'started', 've', '200mg', 'pain', 'months'] | ['he said that at the very least to take prednisone and/or plaquenil (prednisone caused osteoporosis and plaquenil didnâ€™t work), so that he could justify prescribing my pain medication and to continue getting evaluated to monitor my health.', 'iâ€™ve been taking plaquenil for about six years now but have been increasingly having issues with joint pain and fatigue.', 'i was started on plaquenil 300mg daily and a prednisone taper for about 3 weeks which i luckily was able to taper off of. \n\nnow itâ€™s just the plaquenil and meloxicam for joint pain and swelling in my hands.'] |
| 19 | 125 | 19\_mouth\_tongue\_teeth\_jaw | ['mouth', 'tongue', 'teeth', 'jaw', 'painful', 'dentist', 'sores', 'gums', 'jaw pain', 'hurts'] | ["i haven't had mouth sores but i do have what they think is geographic tongue and that gets painful and bad on my tongue.", 'developed mouth sores + swelling on left side of neck and jaw (lie bumps on tongue + painful swollen glands under tongue).', 'Does anyone else get super painful mouth sores on both your tongue and inner cheeks/gums?'] |
| 20 | 108 | 20\_feet\_foot\_toe\_toes | ['feet', 'foot', 'toe', 'toes', 'foot pain', 'pain feet', 'legs', 'ankles', 'ankle', 'big toe'] | ["(undiagnosed) \n\nfor a year i've been having a lot of pain in the soles of my feet (heel mainly), toes/toenails (particularly my left big toe), and some other areas like fingers, knees, etc.", 'i recently broke my foot pretty badly and the er put me on crutches and a walking boot but i canâ€™t put any form of pressure on my foot at all without the most excruciating pain iâ€™ve ever felt and because of my flare my other foot is not strong enough to support me walking (my flares always cause extreme pain or numbness in my feet and hands) and i canâ€™t grab the crutches properly because my hands are weak and canâ€™t grab them very strongly.', 'sesamoid pain in both feet.'] |
| 21 | 104 | 21\_fatigue\_joint\_joint pain\_pain fatigue | ['fatigue', 'joint', 'joint pain', 'pain fatigue', 'joint pain fatigue', 'fatigue joint', 'muscle', 'pain', 'fatigue joint pain', 'joints'] | ['i have had really bad fatigue, joint pain, and just over-all body soreness and tenderness for the past 1.5 years.', 'intense joint pain and fatigue have left me doing mostly nothing my whole day', 'i have it for over 2 years now, it started at the same time with muscle, joint pain and fatigue.'] |
| 22 | 97 | 22\_eye\_eyes\_eye pain\_right eye | ['eye', 'eyes', 'eye pain', 'right eye', 'vision', 'light', 'pain eyes', 'pain eye', 'blurred', 'right'] | ['I began having eye pain.', 'anyone have any suggestions for eye pain.', '2) eye pain-'] |
| 23 | 86 | 23\_fatigue\_pain fatigue\_exhausted\_fatigue pain | ['fatigue', 'pain fatigue', 'exhausted', 'fatigue pain', 'work', 'pain', 'tired', 'job', 'shifts', 'tired pain'] | ["i know most shifts will be 12 hours, and i have done 8 hour shifts at my last job and by maybe 6 hours into that i can't walk so well, like, my arthritis acts up, or i feel fainty, fatigued, nauseous, dizzy, etc.", 'i just feel pathetic because iâ€™m at the point where i am unemployed and desperately trying to find a part-time job, but canâ€™t handle anything physically strenuous or anything that isnâ€™t remote, because i can crash at any point in the day and need to finish my work with my laptop in bed because my body aches, fatigue and swelling are so bad.', 'i already have had to cut back to a per diem position and am only working one 8 hour shift per week instead of my usual 3 12 hour shifts due to this flare up and the pain and fatigue that come with it.'] |
| 24 | 85 | 24\_spasms\_muscle spasms\_muscle\_neck | ['spasms', 'muscle spasms', 'muscle', 'neck', 'shoulder', 'shoulders', 'shoulders neck', 'legs', 'arms', 'neck shoulders'] | ['hello does anyone else get a stomach muscle spasms?', 'is there anything that helps with muscle spasms?', 'anyone else have muscle spasms?'] |
| 25 | 80 | 25\_scalp\_hair\_hurts\_scalp pain | ['scalp', 'hair', 'hurts', 'scalp pain', 'painful', 'tender', 'head', 'touch', 'ponytail', 'pain scalp'] | ['what are you doing for scalp pain and hair loss?', "everything freakin' hurts down to my hair follicles.", 'my scalp hurts.'] |
| 26 | 79 | 26\_tell\_pain\_hurts\_told | ['tell', 'pain', 'hurts', 'told', 'hurts gets', 'iâ', 'tell iâ', 'just', 'sent', 'trying'] | ['he gets annoyed that i tell him that iâ€™m in pain all the time and that iâ€™m worried of my future.', 'it frustrates me that i donâ€™t have down time, and iâ€™m elbow deep scrubbing baked-on egg out of an old pan, while my feet feel bruised on the bottom, one knee is swollen, my fingers feel thick and stiff, my elbows ache just from existing.... if iâ€™m doing all that with all this crap going on, then why does he make it sound like iâ€™m a controlling perfectionist just for asking him to do what heâ€™d said heâ€™d do?\n\niâ€™ve started sleeping in bed with the toddler because itâ€™s less tiring that getting fully woken by walking in with her even on his nights.', 'on a regular basis he claims he is trying to help me by pushing my sore spots to work them out, i ask him to stop because it hurts,but he gets defensive and then upset saying he is just trying to help.'] |
| 27 | 79 | 27\_aches\_ache\_thighs\_body | ['aches', 'ache', 'thighs', 'body', 'muscle', 'muscle aches', 'body aches', 'tendon', 'like', 'legs'] | ['i get aches here and there', 'muscle aches .', 'and my body still aches.'] |
| 28 | 78 | 28\_cramps\_period\_birth control\_birth | ['cramps', 'period', 'birth control', 'birth', 'bleeding', 'menstrual cramps', 'menstrual', 'control', 'cramping', 'periods'] | ['there are several alternatives for birth control to help in order to alleviate bad menstrual cramps.', 'i get pre menstrual cramps, post menstrual cramps, menstrual cramps and ovulation cramps.', '[\*\*what are some good alternatives to birth control for bad menstrual cramps?\*\*](https://www.quora.com/what-are-some-good-alternatives-to-birth-control-for-bad-menstrual-cramps)'] |
| 29 | 74 | 29\_dose\_taking\_stomach\_day | ['dose', 'taking', 'stomach', 'day', 'took', '5mg', 'started', 'iâ', 'medication', 'mg'] | ['I took my second dose on Friday and started getting stomach pain Monday.', 'but it was all horrible\n\ntoday i have not taken it yet as i am too scared, i feel like i want to give my body one day of rest, when i am drinking lots of water and eating bland foods\n\ni am not sure if it was something i ate (instead of the hydroxy) but it felt very violent and painful\n\ni was reading the previous posts and some people take them two together, some people said take it in the day, some people said take them before bed, and most people said it gets better after a few days/weeks and that taking them with food helps\n\nany other ideas would be greatly appreciated!', 'but it still makes me feel terrible iâ€™ve had horrible stomach pains iâ€™ve felt dizzy i donâ€™t feel like eating anymore iâ€™ve had constant random nosebleeds which are new and at this point iâ€™m too scared to take it but thereâ€™s that constant paranoia that if i donâ€™t iâ€™ll affect my future iâ€™ve talked with my doctor i still donâ€™t have a god damn choice my dose is just half a pill at this point so there is no option of reducing anymore i am tired of this pill'] |
| 30 | 70 | 30\_cbd\_cannabis\_marijuana\_thc | ['cbd', 'cannabis', 'marijuana', 'thc', 'help', 'smoke', 'weed', 'relief', 'use', 'medical'] | ['anyone have experience taking thc/cbd to help with their pain from lupus?', 'has anyone tried cbd/thc salves or oils that help with acute pain?', 'How does yalls rheumatologist feel about cbd as an addition for the pain relief?'] |
| 31 | 67 | 31\_rib\_ribs\_cage\_rib cage | ['rib', 'ribs', 'cage', 'rib cage', 'rib pain', 'pain rib', 'left rib', 'sternum', 'left', 'pain ribs'] | ['Also some pain under / around my left rib cage, similar to pericarditis.', 'the last 2-3 months iâ€™ve had pain below my rib cage on my back.', 'but then i started cramping around my rib cage and my back.'] |
| 32 | 62 | 32\_sle\_diagnosed sle\_diagnosed\_ago | ['sle', 'diagnosed sle', 'diagnosed', 'ago', 'years', 'months', 'symptoms', 'hi', 'hi diagnosed', 'fatigue'] | ['i have no symptoms or problems now.\nwas diagnosed with sle over an year ago with no joint or muscle pain.', 'I was diagnosed with SLE in October after months of pain, fatigue, and numerous other symptoms.', 'i was diagnosed with sle in july following years of aches and pains and a big old rash on both my arms.'] |
| 33 | 62 | 33\_painful\_painful just\_uncomfortable\_painful hurts | ['painful', 'painful just', 'uncomfortable', 'painful hurts', 'pain painful', 'hurts', 'painful annoying', 'necessarily painful', 'uncomfortable painful', 'painful uncomfortable'] | ["It's not painful", "it's so painful", 'how painful is it?'] |
| 34 | 61 | 34\_lymph\_nodes\_lymph nodes\_swollen | ['lymph', 'nodes', 'lymph nodes', 'swollen', 'node', 'swollen lymph', 'lymph node', 'swollen lymph nodes', 'lymph nodes neck', 'neck'] | ['my lymph nodes are always swollen and when i drank alcohol, my lymph nodes used to get huge and painful.', 'so, now i can feel the lymph nodes in my chest are swollen, the lymph nodes under my left armpit are swollen and are so painful.', 'this is probably really niche, but does anyone get painful swollen lymph nodes right under their ears, by their jaw?'] |
| 35 | 58 | 35\_arthritis\_arthritis just\_arthritis hands\_hands | ['arthritis', 'arthritis just', 'arthritis hands', 'hands', 'finger', 'thought', 'inflammatory arthritis', '16 iâ', 'middle finger', '16 iâ ve'] | ['when i was 16 after iâ€™ve lost my brother i developed something called trigger finger( my middle finger would get stuck because my tendon would get very inflamed), then my there was an inflammation in my shoulder that was causing me loads of pain.', 'still have arthritis, what a shocker.', 'I had the arthritis in my hands.'] |
| 36 | 58 | 36\_itâ\_painful itâ\_painful\_itâ like | ['itâ', 'painful itâ', 'painful', 'itâ like', 'ðÿ', 'pain itâ', 'ðÿ ðÿ', 'like', 'painful itâ like', 'itâ painful'] | ['itâ€™s not like it hurts', 'itâ€™s very painful.', 'Itâ€™s painful'] |
| 37 | 54 | 37\_shoulder\_shoulder pain\_arm\_left shoulder | ['shoulder', 'shoulder pain', 'arm', 'left shoulder', 'pain shoulder', 'left', 'left arm', 'right shoulder', 'shoulders', 'pain left'] | ['then i get a pain in my shoulder.', 'my shoulder pain was still there', 'my shoulder pain was still there'] |
| 38 | 54 | 38\_hip\_hip pain\_right hip\_right | ['hip', 'hip pain', 'right hip', 'right', 'sciatica', 'pain hip', 'walk', 'pain', 'pain right', 'born'] | ['anyone deal with intense si joint/hip pain?\n\nsaturday, i randomly woke up with lower back/hip pain.', 'what do yâ€™all do for hip pain?', 'i had a bit of hip pain when seated too long.'] |