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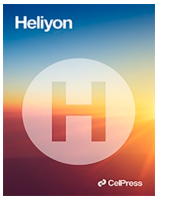

How do immunocompromised people experience the changes in their working lives during the COVID-19 pandemic? Results from a mixed-methods study in Germany

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ABSTRACT

Background and aims: The COVID-19 pandemic has a major impact on many areas of life, including many people's job situations. Not everyone is affected in the same way - people with chronic conditions may experience increased mental stress and social problems. In this study, we focus on immunocompromised people (ICP), who are at high risk for a severe course of COVID-19. Our aim was to investigate the level of social participation during the pandemic, focusing on how ICPs perceive changes in their working lives.

Methods: We applied a mixed-methods concurrent triangulation design with qualitative interviews (N = 13) and a quantitative cross-sectional survey with N = 179 participants. This approach allowed us to gain deep insights into the experience of occupational-social participation.

Results: Qualitative results show that working from home during the COVID-19 pandemic was seen as a relief by many, as medical necessities could be integrated more easily into everyday life. Understanding and consideration of their professional social network were essential for all respondents. Our interview data hint at an influence of the family situation (e.g., having children) and the relationship of the ICP to coworkers on the perception of changes to their work environment. The quantitative results indicate an interaction between mental health and employment status on social participation, with employment reducing the negative impact of poorer mental health on social participation after adjusting for sociodemographic variables.

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Conclusions: Our results indicate changes necessary to integrate people with chronic conditions into working life, even under pandemic conditions. This includes the possibility of flexible working hours and compliance with hygiene measures at the workplace.

1. Introduction

The coronavirus disease 2019 (COVID-19) pandemic not only directly impacts health but also affects people worldwide in social areas of life such as their family lives and work. However, not all people are equally affected [1]. Having certain chronic health conditions, higher age, or immunosuppression makes a severe course of COVID-19 more likely [2]. Immunocompromised people (ICP) are defined as people with an "iatrogenic suppression of certain components of the immune system" in which "the resulting immunodeficiency is either required for medical reasons […] or is a side effect of medical treatment" [3]. The therapy of autoimmune diseases such as inflammatory bowel disease (IBD) or rheumatoid arthritis thus involves an impairment of the immune system. Examples of immunosuppressants are methotrexate, azathioprine and certain monoclonal antibodies ("biologicals"). As described for other vaccine-preventable diseases, immunosuppression increases the risk for severe courses of COVID-19 [4,5]. There is evidence that infectious diseases can exacerbate existing autoimmune diseases or trigger an episode [6,7]. ICPs are advised to be particularly vigilant in adhering to infection-control measures. In comparison to people without this medical condition, they have an increased level of concern about infection and may experience increased anxiety [8,9].

The self-perception of being vulnerable may also impede mental well-being and social life of those concerned [10–12]. People with chronic conditions and disabilities have shown to be particularly susceptible to stress during the pandemic [13,14].

This study aims to investigate challenges to everyday professional life among people with immunosuppression during the COVID-19 pandemic by applying a mixed methods approach. Our work contributes to existing literature examining the effects of the COVID-19 pandemic on vulnerable groups like people with chronic diseases. We would like to inform current research, policy, and practice about the experiences of the population of ICP, which has received little attention to date. We focus on the following main research question: To what extent do changes in work life during the COVID-19 pandemic occur as burden or relief for ICPs regarding their health situation?

2. Methods

In this study, we used a mixed-methods concurrent triangulation design to examine social participation during the COVID-19 pandemic from different perspectives. We focused on ICPs' experience of changes to the work environment. Our study is part of

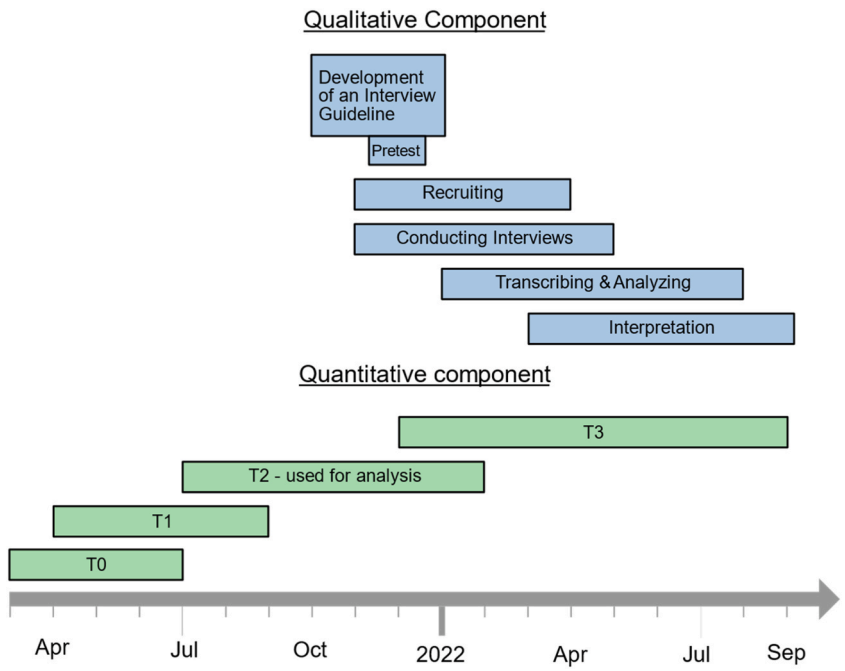

Fig. 1. Study timeline
T0: before COVID-19 vaccination; T1: one month after COVID-19 vaccination; T2: 6 months after COVID-19 vaccination; T3: 12 months after COVID-19 vaccination.

the COVID-19 Contact (CoCo) Immune study. Starting in March 2021, the longitudinal, prospective, two-centered study was conducted to investigate the humoral response of the COVID-19 vaccination and possible effects on social participation in ICPs [15]. In the quantitative part of the study, standardized questionnaires were used at four different time points before and after vaccination. Results indicated that many surveyed ICPs paused their immunosuppressive medication before or during vaccination. Moreover, data showed an increase in ICPs' social participation after vaccination.

To gain deeper insights into the perception of possible challenges to social life during the pandemic, we concurrently conducted and analyzed semi-structured in-depth interviews.

This paper follows the recommendations for Good Reporting of a mixed-methods Study (GRAMMS) described by O'Cathain et al. [16]. The study was approved by the research ethics board of Hannover Medical School (9948_BO_K_2021) and University Medical Center Göttingen (39/8/21). The study timeline is shown in Fig. 1.

2.1. Development of an interview guideline

To identify relevant topics for our qualitative research, we conducted open discussions with ICP. We randomly selected four participants from the CoCo Immune study cohort and asked them to identify those aspects of their everyday lives in which they felt affected by the pandemic. The information gained from this served as a basis for developing an interview guideline.

The interview guideline was reviewed by the research team after conducting five pretest interviews. The research team adopted the guideline after some minor refining were made, e.g., removing questions irrelevant to the research question. The final version contained 29 items including different topics such as personal health situations, family life, occupation, and perceptions of political decisions and social conditions during the COVID-19 pandemic. The interview guideline can be found in the online appendix.

2.2. Cohorts

Recruitment started in March 2021. The quantitative survey cohort consisted of 275 participants in total. Out of this sample, five participants were randomly selected for our qualitative study. Aiming at maximum variability, we expanded the qualitative cohort by nine additional subjects from outside the CoCo Immune Study.

Participants were included in the quantitative study if they were a) 18 years or older, b) able to provide informed consent, c) proficient in the German language, d) planning to be vaccinated against COVID-19 or had already been vaccinated, and e) regularly taking immunosuppressive medication. A definition of medication causing a relevant immunodeficiency can be gathered from the CoCo Immune Study protocol [17]. Exclusion criteria included a) refusal/inability to provide informed consent (e.g., due to mental health conditions) and b) contraindication to blood testing. In the qualitative component, people were included regardless of their intent to be vaccinated (inclusion criteria d) and exclusion criteria b) were not applied in this process).

2.3. Recruitment strategies and sample size

Used recruitment strategies in the quantitative study included local media reports, posters, and leaflets in general practices, mass vaccination sites, and hospitals. During the qualitative component, we additionally applied snowball recruitment methods and advertised the project during a video conference of a self-support group for people with rheumatological diseases in March 2022. Interested participants who contacted the study team and were eligible were subsequently enrolled in the study.

We decided to limit our qualitative research projects to 13 interviews due to limitations of time and human resources. The sample size corresponds to common recommendations on good qualitative research practice, which suggest conducting at least twelve interviews [18–21].

2.4. Research ethics

The entire study was conducted in a contact-minimized manner to minimize the risk of a SARS-CoV-2 infection. Enrollment and obtaining consent from participants were performed by video teleconference, phone calls, or in person based on the reference of the participants. There were no personal relationships established between the interviewer and the participants prior to the study. All participants received a compensation for participating in the interviews of €40.

2.5. Data collection

2.5.1. Qualitative component

Due to the risk of a severe course of COVID-19 that ICPs face, we conducted interviews using the video conference software Zoom (Zoom Video Communications Inc., San Jose, CA) and used the recording function to tape audio. Participants joined the video conference from their homes. Only the individual participant and the researcher were present at their meeting.

Due to a lack of digital literacy, one participant declined to be interviewed remotely and requested a personal interview which we carried out in a 1:1 setting at the research institute in Göttingen.

Participants were informed prior to the interview about the objectives of the project and about the privacy and data safety regulations. Participants declared written informed consent by filling out and signing a consent form which was then sent to the researchers by either mail or fax.

Interviews were conducted between November 25, 2021, and May 10, 2022, by a male sociologist with experience in qualitative research (SR).

The audio recordings of the 13 in-depth interviews were transcribed verbatim following Dresing and Pehl [22]. Transcripts were checked for accuracy by one of the researchers (SR) not involved in the transcription.

2.5.2. Quantitative component

Data used for this study were collected 6 months after COVID-19 vaccination) by a researcher experienced in quantitative methods (DS). Sociodemographic data including gender, age, household situation, and employment status were collected at study inclusion. Two scales seemed useable to generate data on changes to the perception of the ICPs' work environment in the quantitative part of our study.

The measure for social participation is the validated Pandemic Social Participation Questionnaire (PSP-Q) [23]. It was developed in 2020 during the first year of the COVID-19 pandemic to reflect social participation in the pandemic setting. It consists of 14 items which are rated on a five-point Likert scale ranging from 1 = strongly agree to 5 = strongly disagree. Higher scores indicate higher social participation with scores ranging between 14 and 70. The second scale is the validated Patient Health Questionnaire-4 (PHQ-4) which is a four-item scale used to screen for depression and anxiety symptoms [24]. An overall psychological distress sum score ranging between 0 and 12 can be calculated. Higher scores indicate higher anxiety and depression symptoms with values $\geq$ 6 indicating symptoms of clinically relevant anxiety or depression symptoms [25].

Additionally, the subjective current health status was collected using one item with a five-point Likert scale (1 = best health; 5 = worst health). Detailed information on data collection can be found in Schröder et al. [26].

2.6. Analyses

Qualitative and quantitative data were analyzed concurrently. Data integration was conducted afterward and during the interpretation phase.

2.6.1. Qualitative phase

Interviews were analyzed using qualitative content analyses by Mayring [27]. In an iterative and discursive process, three team members (GW, SR, and TS) developed a category system using both deductive and inductive categorization. A first version of the category system was created deductively using the main topics of the interview guide. Subsequently, it was expanded inductively by GW, SR, and TS. Categorizations were discussed repeatedly within the team and a codebook was developed including definitions of the codes, anchor examples, and coding rules. We identified a total of seven main categories with up to two further category levels. After coding all interviews, paraphrases, and generalizations were derived from the respondents' statements. Generalizations were compared and interpreted theoretically and empirically. Data saturation was discussed within the team and considered to have been reached in relevant themes following existing literature [18–21]. MAXQDA Version 2022.3 (VERBI Software GmbH, Berlin, Germany) was used to evaluate all data.

An overview of the categories generated in this analysis can be found as a supplement to this article. The main themes are reported in the results chapter, and relevant citations from the interviews are translated from German into English using forward translation. "p" stands for participants.

2.6.2. Quantitative component: statistical analysis

Data from the time point six months after COVID-19 vaccination was used for statistical analysis as this time point was closest to the interviews. Participants were excluded if they had missing values. Additionally, the five interview participants were also excluded from the quantitative study part to ensure the independence of both approaches and increase the generalization of our results.

Participant characteristics were reported using absolute numbers and proportions for categorical variables and mean and standard deviation for numeric variables. To quantify the effect of employment status, sociodemographic variables, mental health (PHQ-4), and current health status on social participation (PSP-Q) a linear regression was conducted. Three regression models were included. Model 1 included only the employment status as the independent variable. Model 2 adds sociodemographic factors, and Model 3 additionally adds the PHQ-4, current health status, and interaction between employment status and the PHQ-4 as independent variables.

Qualitative results are presented in the following section followed by quantitative results.

3. Results

3.1. Qualitative component

A total of 15 immunocompromised participants were recruited, and 13 interviews were analyzed. One participant withdrew from participating in an interview after recruitment and another participant was subsequently excluded as we became aware during the interview that he did not match the inclusion criteria (no regular intake of immunosuppressive medication). Sociodemographic and medical characteristics of study participants are presented in Table 1.

Interviews had an average duration of 42 min (min 29, max 61 min, SD 10.85). Aspects mentioned by interviewees varied according to different occupational areas. The study sample covers a wide range of occupations and work styles, which is presented in Table 2.

3.1.1. Work from home

For five participants, working from home was experienced as a relief. Since being immunosuppressed had previously led to absenteeism and stress in work life, study participants with office-based jobs found the possibility of flexible working hours particularly relieving regarding their chronic illness and immunosuppression. Planning and attending medical appointments were easier, as was recovering from therapy and its side effects like fatigue by taking breaks during day-to-day work. One 43-year-old female office-based employee described how working from home made it easier for her to integrate her health restriction into her everyday working life:

> "With the Covid management in place, it has become a little easier to keep medical appointments because I can work more flexibly. As far as I'm concerned, Corona can stay. Now that I'm working from home, I can take an hour or two off in between […]. When I have a headache or when I've been throwing up, as has happened recently, it's just easier to handle now. Where before I would call in sick a lot more frequently, now I just lie in bed for a couple of hours and answer the phone when someone calls and somehow fight my way through the day that way." (p 13)

Another female 50-year-old respondent working as a clerk even perceived a positive effect on her health by working from home. Whereas the immunosuppression reduced her resilience to stressors at work before, stress relief by working in a "safe" environment led to an improvement in her ability to work now:

> "I like working very much, and my big wish is to work until retirement, if possible. And what supports my achieving this wish definitely is that I can work from home, it makes it easier for me to avoid 'stressors', so to speak. And if I were to have more freedom, that is, if I were given corresponding trust and appreciation of my work as such … just because I am ill, I am not a bad employee. " (p 10).

For this interviewee, the desire arose to maintain flexible working hours. After becoming used to restricted social contact, she found it very difficult to return to old social behaviors and working processes. This was associated with discomfort:

> "The biggest challenge at the moment is to return to a certain normality or to encounters, to more encounters also in the professional context. Just as it was a problem at the beginning to go into loneliness, as I'm calling it now, to go home, to work alone at your workplace, you got used to it over two years. And now you have to return, I think that is currently just the biggest challenge, and then also at the same time to accept that I thereby again have immensely more contact with people through the consulting activity. " (p 10).

Three participants highlighted that the change to working from home resulted in a higher workload for them. In addition, losing professional contacts triggered a feeling of social isolation. A 28-year-old female respondent said:

> "And then I was actually exclusively working from home. I had a very great team, too, but I missed personal contact a lot. I felt quite alone there, even though I got on well with the people. But at first, there were still too few meetings, and I felt very alone in my office, and it was not very motivating. " (p 9)

3.1.2. Reconciling work and children

Caring for and raising children in addition to work placed an extraordinary burden on some ICPs. One 40-year-old single mother waived her existing entitlement to the state support offer of emergency childcare during one lockdown. Instead, to protect her family and herself from contracting COVID-19, she organized her own childcare with creativity and with the support of her social circle. The

Table 1
Sociodemographic and medical characteristics of interview study participants (N = 13).

Participants' demographic characteristics	Frequency (N)	Share (%)
Age		
<40	4	30.8
40–65	7	53.9
>65	2	15.4
Gender		
Female	9	69.2
Male	4	30.8
Nationality		
German	13	100
Family status		
Married	8	61.5
Parenting	8	61.5
Underlying disease		
Inflammatory bowel disease	6	46.2
Rheumatological disease	6	46.2
Other	1	7.7
Number of taken immunosuppressants		
1	10	76.9
2	3	23.1

Table 2
Occupations, working hours, and working methods of the respondents (N = 13).

Respondent	Occupation	Working part-time	Possibility to work from home
1	Retired[a]		
2	Car salesman		✓
3	Deputy head of nursing		
4	Employee at a health insurance company	✓	✓
5	Process manager (maintenance)		✓
6	Student (with part-time job)		✓
7	Retired[a]		
8	Speech therapist	✓	
9	Student (with part-time job)		✓
10	Clerk at a university, civil service		✓
11	Dentist with own practice		
12	Administrative assistant (event planning)	✓	✓
13	Architect (Office activity)		✓

[a] Retired respondents are listed here to fully display the sample. They were not included in the analysis of changes to the work environment.

reason for this behavior was her vulnerability to COVID-19 because of her immunosuppression.

In the following, the stress of everyday life multiplied due to the high workload as a professional and mother during the COVID-19 pandemic and had a negative impact on her health:

> "We then sort of organized an exclusive play partnership with my son with another child, […] because otherwise, I have to say quite honestly, I was hanging on by the skin of my teeth. I worked when I found a gap at that time, no matter where or when. It could have been early in the morning or sometimes an hour in the morning or then again at night, or then sitting in front of the TV for an extra hour with the child because some important meeting had to be prepared or something. " (p 4).

3.1.3. Understanding of superiors and colleagues

A majority of the participants in this survey described their superiors at work as considerate and left a positive impression of the decision and implementation of protective measures to make their workplace safe. This made them feel safe as part of a vulnerable group during the COVID-19 pandemic. For many, this included the possibility to work from home, as described by a female 50-year-old clerk:

> "I felt really, really well protected and understood. My needs as a whole, but also those of each individual, were really taken into consideration. So, at the beginning, it was actually the case that, if you belonged to a vulnerable group of people with a higher risk of infection, we were allowed to stay at home completely, I thought that was very good. " (p 10)

Only one 41-year-old male respondent, working in the car trade, expressed strong dissatisfaction with his employer's handling of the pandemic situation: *"Well, if you had to express it in grades, then my employer would receive fail grades from me in every respect as far as this issue of the Corona pandemic is concerned. There are many, there are many things that certainly play a role that are not right here at this point." (p 2)*

In the interviewee's case, resentment also arose among their coworkers. It culminated in offensive and envious reactions to him being highly prioritized for vaccination due to his chronic condition: *"They expressed envy then; they were envious. Like how you are already vaccinated? How come? You're much younger than me and so on."* (p 2).

> Disagreements with coworkers were also reported by a deputy head of nursing. She described discussions about the COVID-19 vaccination that led to dissatisfaction within the team: *"Actually, all of us are vaccinated, except for one coworker, who gets shamed a little bit [by her coworkers] but who then says: 'If this continues, I'll quit.'"* (p 3). Another person mentioned special regulations granted to ICPs by superiors as a reason for insecurities in her working environment.
>
> *"[…] but because I had withdrawn very much last year […], I had to say: 'I'm not going to get on the train and come to the office in Berlin now. For me, that's not because it just didn't fit me timely, but because of my health. Basically, there was some understanding, but the longer the situation [the COVID-19 pandemic] persists, I'm not so sure about peoples' [the interviewees coworkers] acceptance, because you might be less approachable than coworkers who aren't affected by it."* (p 4)

The initial understanding on the part of coworkers and especially superiors for her health situation diminished in the course of the pandemic:

> "But there was also a slackening effect over time, the longer it lasted, until now. I have the impression that it is again expected that we actually manage everything as if we had no pandemic. In any case, targets have not been reduced or adjusted […]." (p 4)

This led to lower job satisfaction among the respondents concerned. However, a large proportion of ICP felt comfortable not only with their superiors but also with their professional social contacts despite working at a distance.

3.1.4. Importance of measures to prevent COVID-19 infection at work

Some participants emphasized that they were concerned about a COVID-19 infection at work. This reinforced their unease, which already existed before the COVID-19 pandemic due to the immunosuppression. A 42-year-old female administrative assistant stated:

> "The problem with me is that I meet a lot of people, and that's just natural. There is always the fear. You don't want to shake hands with these hundreds of people in one evening, and it has become more acute because of the immunosuppression therapy and then again because of Corona. And the joy of meeting a lot of people is somewhat reduced, obviously. But that's just one part of my job, but it's not quite as nice anymore. " (p 12)

The interviewees found it difficult when the professional environment had little accommodation of the special needs and health protective measures even before the pandemic: *"It was also the stupid way of always shaking hands with everyone, and you always felt a bit like a leper, so to speak, when you said: I don't like to shake hands here now." (p 5)*. Therefore, the implementation of hygiene measures and social distancing in the work environment was perceived as a positive development by some of the ICP, regardless of the COVID-19 pandemic: *"And then Corona came, and then everyone provided it [disinfectants] on the table and everyone was disinfecting their hands. But that was actually quite good. As I said, the awareness for a bit more hygiene and what belongs to it is simply more present. I think that's nice." (p 12)*.

There was a desire among many interviewees to maintain measures such as distance rules and the provision of disinfectants in the workplace even after the COVID-19 pandemic.

3.2. Quantitative component

In total 275 ICPs were recruited. Five participants were excluded because they participated in the qualitative study and 54 participants were loss-to-follow-up. 35 participants did not provide information for all in the analysis included variables and were therefore excluded. Characteristics of the included participants are presented in Table 3. Additional information on participants' immunosuppressive medication can be found in Table 4.

Before the analysis, we assumed a relationship between social participation and the household situation, e.g., raising children. Therefore, the variables "raising children" and "living alone" were included in the regression analysis as possible confounders. Employment status was significantly associated with lower PSP-Q scores in bivariate analysis ($\beta = -3.48$, $t\,(177) = 1.99$, $p = .048$). When including sociodemographic variables as additional variables in the model, only the variable age was significantly associated with PSP-Q scores. Age was positively associated with higher PSP-Q scores after adjusting for other sociodemographic factors ($\beta =$

Table 3
Sociodemographic and medical characteristics of quantitative study participants (N = 179).

Participants Demographic Characteristics	Frequency (N)	Share (%)
Gender		
Male	46	25.7
Female	133	74.3
Age (mean (SD))	56.89	15.55
School education[b]		
Low	20	11.2
Middle	53	29.6
High	106	59.2
Employment		
Yes	94	52.5
Raising children		
Yes	35	19.6
Living alone		
Yes	39	21.8
PHQ-4 (mean (SD))	2.79	2.4
PHQ-4 $\geq$ 6	19	10.6
Subjective health status (mean (SD))[2]	3.26	1.2
Underlying condition[a]		
Rheumatological condition	66	36.9
Inflammatory bowel disease	24	13.4
Psoriasis	25	14.0
Multiple sclerosis	18	10.1
Solid organ transplant	13	7.3
Other	39	21.8
Number of taken immunosuppressants		
1	93	52.0
2	50	27.9
3	15	8.4
4	1	0.6

[a] Multiple selection possible.
[b] based on German secondary school education.

0.17, t (171) = 2.49, p = .018).

After including PHQ-4 scores and health status, a negative significant association between PHQ-4 scores and PSP-Q scores could be observed (β = -3.40, t (168) = 5.77, p < .001). PSP-Q scores were positively associated with self-reported health status (β = −1.42, t (168) = 2.06, p = .041). The interaction between employment status and PHQ-4 scores on PSP-Q scores indicated a significant weaker relationship between PHQ-4 and PSP-Q scores in employed participants compared to unemployed participants (β = 1.46, t (168) = 2.22, p = .028). In contrast to the second model, age was not significantly associated with PSP-Q scores after adding health status and PHQ-4 scores in the regression model. The explained variance for each model is additionally presented in Table 5. Fig. 2 presents the interaction between mental health and employment status on social participation.

4. Discussion

With our mixed methods study, we intended to obtain insights into the perception of social participation in ICP during the COVID-19 pandemic. Qualitative results show divergences in ICPs' perception of changes in the workplace. Besides some reinforced stressors, people perceived working from home as beneficial. Qualitative data hints at a relationship between having children and social participation. Quantitative data indicates an indirect effect of work on ICPs' social participation through mental health after adjusting sociodemographic variables and subjective health status. Our results go along with existing literature confirming that unemployment has negative effects on mental health in people with chronic conditions like IBD [28,29].

Results can be partly explained by experiences independent from ICPs' underlying condition and are comparable to the experiences of the general population. However, individual reports also indicate that immunosuppression requires special protective measures in the occupational environment.

Relevant topics revealed in the qualitative interviews and quantitative data are discussed in the following.

4.1. Perception of working from home

Measures such as closed offices and working from home proved to be effective in slowing down the spread of the virus [30–32]. Even though a majority of employees rated this change rather positively [33,34], some authors suggested increased social isolation [35] and a deterioration in physical and mental health, as well as an increase of new health problems [36]. Our qualitative findings show divergences in the experiences of participants concerning the shift to working from home. While a burden due to the loss of professional-social contacts was paramount for some ICPs, many others perceived the flexible work schedule as a relief from their illness. The sociologists Berger and Luckmann [37] emphasized that in the "social construction of reality," work is an important *zone* of everyday life. This everyday life forms a part of reality in which interaction takes place vis-à-vis. The loss of contact in the professional world caused by the switch to working from home led to a reduction of this vis-à-vis interaction. The different evaluations of this occupational change can be explained based on this sociological theory. Depending on whether the interviewees considered professional-social contacts as part of the inner social circle or whether they had a rather superficial relationship with coworkers [37], working at a distance tended to be perceived negatively or positively.

Table 4
Drugs subdivided according to active ingredient groups (N = 179).

Immunosuppressive medication	N (%)
DMARDs	25 (14.0)
Glucocorticoid	47 (26.3)
TNF inhibitors	23 (12.8)
S1P	11 (6.1)
JAKi	9 (5.0)
IL23/IL17	11 (6.1)
Anti-CD20	7 (3.9)
Integrin	4 (2.2)
Other	38 (21.2)
Missing	20 (11.1)

Multiple selection possible.
Immunosuppressive medications were categorized in the following groups: DMARDs (Methotrexate, Azathioprine, Leflunomide, Hydroxychloroquine, Sulfasalazine); Glucocorticoid (Prednisolone, Cortisone, Budesonide); TNF inhibitor (Adalimumab, Etanercept, Infliximab, Golimumab, Certolizumab); S1P (Fingolimod, Glatirameracetat, Siponimod); Janus kinase inhibitor (JAKi) (Upadacitinib, Tofacitinib, Baricitinib); IL23/IL17 (Ustekinumab, Guselkumab, Secukinumab, Ixekizumab); Anti-CD20 (Rituximab, Ocrelizumab); Integrin-based therapeutics (Vedolizumab, Natalizumab); Others (e.g., Peginterferon, Dimethylfumarat, Ibrutinib, Apremilast, Mercaptopurine, Sirolimus).

Table 5
Regression model predicting PSP-Q scores (social participation).

	Model 1	Model 2	Model 3
	Coefficients (95% CI)		
Employment			
Yes	−3.48 (−6.93; −0.03)*	−0.40 (−3.43; 3.52)	−4.50 (−9.51; 0.50)
No	- (ref)	- (ref)	- (ref)
Gender			
Male		- (ref)	- (ref)
Female		−3.69 (−7.83; 0.45)	−0.15 (−3.67; 3.36)
Age (per year)		0.17 (0.03; 0.31)	0.05 (−0.08; 0.17)
School education			
Low		- (ref)	- (ref)
Middle		−2.29 (−8.48; 3.90)	−2.28 (−7.47; 2.91)
High		−3.19 (−9.12; 2.74)	−1.84 (−6.75; 3.08)
Raising children			
Yes		3.53 (−1.27; 8.34)	3.38 (−0.59; 7.34)
No		- (ref)	- (ref)
Living alone			
Yes		1.93 (−2.42; 6.28)	2.71 (−0.89; 6.30)
No		- (ref)	- (ref)
PHQ-4 (per score) [1]			−3.48 (−4.57; −2.24)*
Subjective health status (per score) [2]			−1.42 (−2.78; −0.06)*
PHQ-4*Employment			
yes			1.46 (0.16; 2.76)*
no			- (ref)
R [2]	0.022	0.094	0.396

*p < .05; PHQ-4: Patient Health Questionnaire 4; [1]Score 0–9 (higher scores indicate a higher level of anxiety and depression symptoms [2]; measured on a five-point Likert-scale (higher scores indicate lower health status).

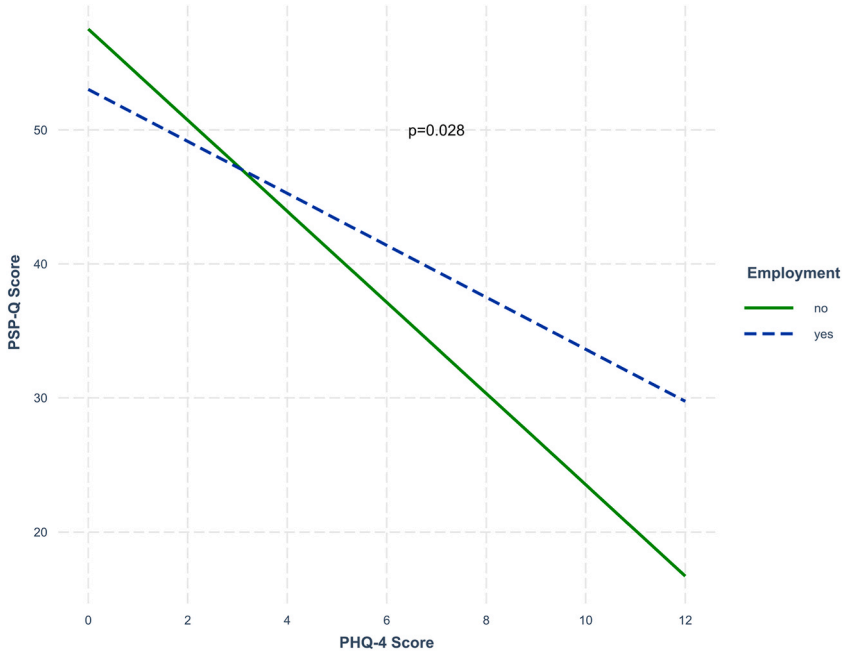

Fig. 2. Interaction between mental health (PHQ-4) and employment status on social participation (PSP-Q).

4.2. Workplace and interpersonal relationships

The perception of the social situation during the COVID-19 pandemic and the lack of solidarity among others in the workplace can be discussed in the context of the actor-network theory [38]. According to them, actors do not act alone, but in networks. With the current situation, individual members or groups of society (e.g., ICP or other chronically ill), institutions (e.g., the state and the health care system), and resources (e.g., vaccines, ventilators, medical masks) constitute the actors in the COVID-19 pandemic network. They interact with each other and, at their best, form a functioning unit. Members of society who do not assume their responsibilities can

become destabilizing factors. For many respondents in our qualitative study, people showed little responsibility during the COVID-19 pandemic when, for example, they refused to receive immunization or failed to adhere to hygiene measures. This behavior can have a negative impact, especially on vulnerable actors in society. This provides a possible explanation for the fact that ICP value consideration and solidarity in a particular way. In comparison to their private life, ICPs are not able to influence the choice of their interaction partners in the professional environment.

Occupational psychologists have shown that interpersonal relationships create meaning at work [39] and that negative relationships experienced in this area correlate with stress, depression, and general health problems [40]. Some ICP described how interpersonal relationships were disrupted due to disagreements on certain topics like COVID-19 vaccination or special treatment offered to ICPs by superiors. This may have impacted participants' mental health. It provides a possible explanation for the significant interaction of mental health and social participation in the employed subsample compared to the not employed subsample of our quantitative survey. Holland and Collins [41] examined the occupational experiences of people with rheumatoid arthritis after they received their diagnosis. The authors reported that collegial support is of great relevance to the ability to work of this group. Additionally, they showed that workplace modifications to support people to stay at work (e.g., specialist equipment or modified hours) can negatively affect their relationships to co-workers. Our qualitative and quantitative results are consistent with this study. For many ICPs, the COVID-19 pandemic revealed the importance of collegial support - especially with an underlying chronic condition. Drake & Wallach describe employment as a critical mental health intervention without harmful side effects even for people with serious mental health illnesses [42]. Employment was also associated with improved social relationships and community integration as we were also able to show in the quantitative study part [42–44]. Chronically ill persons with an employment were 2.3 and 2.1 times more likely to participate in social and cultural events, respectively, compared to unemployed chronically ill persons after adjusting for sociodemographic factors including income. A possible explanation for this association between employment and social participation could be an extended social network which comes with social capital in employed persons, compared to unemployed persons [45].

4.3. Measures to prevent COVID-19 infection at work and flexible working

For some interview participants, introducing hygienic measures at work reinforced a feeling of safety. The desire arose to continue these practices. All respondents were unanimous in their desire for consideration and understanding for their health impairments in their professional environment.

Results show that ICPs wish for flexible working hours and an adjustment of the workload to relieve their stress during the pandemic. Our qualitative data indicated that factors like being a single parent led to additional stress. Quantitative data in contrast did not show a significant correlation between family status and social participation or mental health. This difference may be due to possible confounders in the quantitative study and different sample sizes and compositions. In addition, our qualitative data offered a deeper insight into ICPs' perception and experience of COVID-19-induced changes and allowed us to identify and specify individual stressors.

Existing literature shows that stress can possibly trigger a flare of a chronic disease [46,47] which leads to higher doses of immunosuppressants such as corticosteroids for disease control. The fear of contracting SARS-CoV-2 can additionally cause increased psychological physical and psychological stress [48]. Shorter working hours, working from home, and independence in planning work tasks are measures to help people with chronic conditions to maintain their working ability [49–52].

4.4. Limitations and strengths

To the best of our knowledge, this is the first mixed methods study to explore and evaluate how ICPs experience the changes to their working lives during the COVID-19 pandemic.

A central limitation of the qualitative study is the small sample size ($n = 13$). Even though this sample size is considered sufficient to make axiomatic assumptions and complies with recommendations for interview-based qualitative research [18–21], a more representative sample is needed to derive indications on concrete actions. By offering only questionnaires in the German language in the quantitative phase, we structurally excluded potential participants with limited German language proficiency. Quantitative analysis was based on data from one time point therefore, no causal relationships can be drawn between the variables. Further variables not collected in the quantitative analysis such as comorbidities of the ICPs, may influence social participation. Moreover, there was no control group in the quantitative part of our study.

Qualitative interviews and the quantitative survey were conducted during different stages of the pandemic, which should be taken into consideration when interpreting the results. Subjects may have been influenced by the current infection situation and prevailing rules.

Despite these limitations, our study allows us to gain first deeper insight into social problems in the everyday professional lives of individual ICPs.

5. Conclusion

With our mixed methods study, we provide first insights into the experience and perception of changes to the work environment of ICP in Germany during the COVID-19 pandemic. Qualitative results revealed that changes to how people work are not generally perceived as a burden or relief. Nevertheless, the in-depth analysis of interviews in combination with quantitative data let us point out aspects of great relevance for ICP: (1) Consideration and understanding by superiors and coworkers, (2) compliance with hygienic

measures at the workplace, and (3) the greatest possible flexibility with regard to working hours and, if necessary, the possibility of working from home. Quantitative data indicate mental health as a relevant factor influencing social participation showing a negative association in ICP whereby employment is a protective factor. As the COVID-19 pandemic can exacerbate their physical and psychological complaints, protecting employers with immunosuppression by adjusting work styles individually, is particularly important to maintain the ICP's ability to work. Our findings are relevant to employers and policymakers who need to be more aware of the specific needs of immunosuppressed employees. Eventually, awareness and understanding are required in general to enable the best possible social integration of people with health impairments such as immunosuppression.

Author contribution statement

Greta Sophie Wegener; Tim Schmachtenberg: Analyzed and interpreted the data; Wrote the paper.

Eva Hummers: Conceived and designed the experiments; Wrote the paper.

Frank Müller; Sascha Roder; Alexandra Dopfer-Jablonka: Conceived and designed the experiments; Performed the experiments; Analyzed and interpreted the data; Wrote the paper.

Dominik Schröder: Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Georg M N Behrens; Sandra Steffens: Conceived and designed the experiments.

Data availability statement

Data will be made available on request.

Declarations ethics statement

The study was approved by the research ethics board of Hannover Medical School (9948_BO_K_2021) and University Medical Center Göttingen (39/8/21).

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.heliyon.2023.e20344.

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