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**Taking the strain? Impact of glaucoma on patient's informal caregivers**

McDonald, Leanne<sup>1, 3</sup>; Turnbull, Paula<sup>2</sup>; Chang, Lydia<sup>2</sup>; Crabb, David P.<sup>1</sup>

**Author affiliation:**

1. Optometry and Visual Science, City, University of London, London, United Kingdom.

2. Department of Ophthalmology, North West Anglia NHS Foundation Trust, Hinchingsbrooke Hospital, Huntingdon, United Kingdom.

3. Psychology, School of Human and Social Sciences, University of West London, London, United Kingdom.

**Corresponding author:**

Leanne McDonald, Psychology, School of Human and Social Sciences, University of West London, London, United Kingdom; leanne.mcdonald@uwl.ac.uk.

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No conflicting relationship exists for any author

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## Summary

### What was known before

- Chronic open angle glaucoma (COAG) can cause difficulties with activities of daily living such as driving and mobility.
- Other chronic eye diseases, for example, age related macular degeneration lead to an increase in reliance on family support networks; this is termed informal caregiving.

### What this study adds

- The first to estimate caregiver strain in a sample of COAG caregivers using a validated instrument.
- Informal caregiver strain is negligible in most patients consecutively sampled from a glaucoma clinic in England.
- ICG strain becomes inflated in patients with advanced visual field (VF) loss in COAG.
- ICG strain increases moderately with worsening VF's but in our sample some of this could be explained by worse general health.

## Abstract

**Purpose:** To estimate informal caregiver (ICG) strain in people from a glaucoma clinic.

**Methods:** Patients with glaucoma were consecutively identified from a single clinic in England for a cross-sectional postal survey. The sample was deliberately enriched with a number of patients designated as having advanced glaucoma (visual field [VF] mean deviation worse than -12 dB in both eyes). Patients were asked to identify an ICG who recorded a Modified Caregiver Strain Index (MCSI), a validated 13 item instrument scored on a scale of 0-26. Previous research has indicated mean MCSI to be >10 in Multiple Sclerosis and Parkinson's disease. All participants gave a self-reported measure of general health (EQ5D).

**Results:** Responses from 105 patients (43% of those invited) were analysed; only 38 of the 105 named an ICG. Mean (95% confidence interval [CI]) MCSI was 2.4 (1.3, 3.6) and only three ICGs recorded a MCSI > 7. The percentage of patients with an ICG was much higher in patients with advanced VF loss (82%; 9/11) when compared to those with non-advanced VF loss (31%; 29/94;  $p=0.001$ ). Mean (standard deviation) MCSI was considerably inflated in the advanced patients (5.6 [4.9] vs 1.5 [2.2] for non-advanced;  $p=0.040$ ). Worsening VF and poorer self-reported general health (EQ5D) of the patient were associated with worsening MCSI.

**Conclusion:** ICG strain, as measured by MCSI, for patients with non-advanced glaucoma is negligible, compared to other chronic disease. ICG strain increases moderately with worsening VFs but this could be partly explained by worse general health in our sample of patients.

## 49 Introduction

50 Chronic Open Angle Glaucoma (COAG) can cause slow, irreversible damage to the visual field (VF). COAG,  
 51 like many other chronic conditions affecting older adults, does not limit lifespan but can make life more  
 52 challenging. For example, patients can report significant problems with activities of daily living, such as  
 53 driving, reading and mobility as their VF worsens [1, 2]. Such difficulties may lead to a reliance on a spouse,  
 54 partner, close friend or family member for support [3, 4]. A person caring for someone with a chronic or  
 55 disabling condition, but not in a formal capacity, can be termed an informal caregiver.

56 Informal caregiving, much like the condition that the patient is experiencing, can be a complex issue  
 57 incorporating physical, psychological, financial and emotional changes [5]. When these experiences are  
 58 negative, it is termed caregiver strain [6]. For example, informal caregivers have been shown to experience  
 59 exhaustion, problems with wellbeing and reduced levels of self-esteem [7]. Informal caregiver (ICG) strain is  
 60 most likely to affect women and those who do not have adequate social support [8, 9]. Conversely, ICGs who  
 61 are psychologically well adjusted, have good social support and implement proactive coping strategies are  
 62 less likely to suffer from caregiver strain [6]. ICGs often do not report their caregiver status to healthcare  
 63 professionals and as such may not receive appropriate support [10].

64 ICG strain is well studied in conditions like cancer [11] and mental illness [12] where burden of care is often  
 65 significant. More recently, ICG strain in long-term conditions has received attention. For example, ICG strain  
 66 in Parkinson's disease (PD) and Multiple Sclerosis (MS), was found to be significant when measured  
 67 quantitatively using a modified version of the Caregiver Strain Index (MCSI) [6]. The same may be true for  
 68 long-term chronic eye conditions. For example, ICG strain has recently been described in people with age-  
 69 related macular degeneration (AMD) especially as the condition leads to visual impairment [13, 14, 15, 16,  
 70 17]. Moreover, specific aspects of ICG strain for AMD like that associated with frequent treatment visits to  
 71 clinic have been flagged [14, 16]. There has also been an effort to assess ICG strain in paediatric glaucoma

72 patients [18, 19]. However, there has been no attempt to quantify ICG strain in adult COAG and this is the  
73 main idea presented in this paper.

74 We estimate ICG strain in people in a glaucoma clinic in England. We do this with a cross-sectional study  
75 using a widely used and well validated standardised instrument (MCSI) [20]. We primarily aim to compare  
76 values from this index to values from other chronic conditions where ICG strain has been investigated using  
77 the same measure, specifically those described in Peters et al. (2013) [6]. We test a secondary hypothesis  
78 that measures of worsening VF in COAG are associated with worsening ICG strain as measured by MCSI.

## 79 **Materials and Methods**

80 We designed a cross-sectional study involving patients recruited from the glaucoma clinic of Hinchingsbrook  
 81 Hospital (part of North West Anglia NHS Foundation Trust). The study was approved by the NHS Research  
 82 and Ethics committee of the East of Scotland (17/ES/0044 ref number: 216487) and adhered to the tenets  
 83 of the Declaration of Helsinki. Patient participants were selected consecutively from an Electronic Medical  
 84 Record (EMR) (Medisoft, Leeds, UK) by the study coordinator (PT) and the clinic's main glaucoma consultant  
 85 (LC). To be eligible, patients (>40 years) had to be currently treated for a diagnosis of COAG with visual field  
 86 (VF) loss in at least one eye. COAG suspects and patients with ocular hypertension were excluded.  
 87 Participants were only included if they had no other ocular disease (except for uncomplicated cataract  
 88 extraction) and a corrected binocular visual acuity (VA) of better than LogMAR 0.3 (6/12) at their last clinic  
 89 visit. Patients were selected consecutively from the date they last attended clinic, and this had to be within  
 90 6 months of the data extraction. Names and addresses were recorded along with age (years) and a measure  
 91 of VF loss in both eyes (mean deviation; MD) from their last clinic visit as acquired using a Humphrey Field  
 92 Analyser (Carl Zeiss Meditec, Dublin, CA). The EMR also has a field for the number of significant non-ocular  
 93 co-morbidities and this number was recorded too.

94 We aimed to select a total of 250 patients representing a population of people with COAG being treated in  
 95 a clinic in England (see data analysis; sample size). We deliberately aimed to include 50 patients (some  
 96 selected non-consecutively) designated as having advanced COAG defined as MD worse than -12 dB in both  
 97 eyes. This measure for advanced VF loss has been widely used before in, for example, health economic  
 98 evaluations of COAG and coincides with a high-likelihood that the patient does not satisfy the VF component  
 99 for legal fitness to drive [21, 22].

100 A questionnaire pack, including a participant information document, was posted to the address of selected  
 101 participants. Due to the postal nature of the survey, participants were asked to complete a statement of  
 102 implied consent. The patient information document asked participants to identify an informal caregiver (if

applicable) with the following question: *'Can you identify someone who is an informal caregiver for your glaucoma? This might be a spouse, a partner, a relative or friend who helps you with any aspect related to your glaucoma.'*

The questionnaire pack included two sections printed on different coloured paper, one for the patient and one for their potential informal caregiver (ICG). The patient section had demographic questions and a validated instrument (EQ5D) to measure self-reported general health. EQ5D is commonly used by NICE (The National Institute for Health and Care Excellence) for health economic evaluations for clinical interventions. We used EQ5D-5L in which items are scored from 1 (no problems) to 5 (severe problems) on the five domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. An EQ5D index score was generated in a standard way with 1 representing full health (a score of 1 on all five items), and on the basis of a so-called UK tariff (applicable to our participants), a worst health state of -0.594 [23].

If an ICG was identified by the patient, then they completed a separate section of the questionnaire with its own consent statement; this included demographic questions, the EQ5D and MCSI questionnaires [20]. MCSI has been widely used with more than 200 citations in the literature. MCSI estimates levels of ICG strain in terms of financial, physical, psychological, social, and personal strain using 13 items, each of which is scored 'yes, regularly', 'yes, sometimes' or 'no'. Scores range from 0 ('no' on all items) to 26 ('yes, regularly' on all items).

The questionnaire pack was sent with two stamped-addressed envelopes to ensure that responses could be returned privately. A 'thank you' note/reminder was sent two weeks later to encourage responses. Data from the questionnaires was double entered. Median imputation was used for any missing values. Data was anonymised and stored in a secure location.

## **Data analysis**



Our primary outcome was mean MCSI in the ICGs of the participating patients and a comparison with values reported from a study by Peters et al. for ICGs for people with MS and PD [6]; these values were 11 and 12 respectively. We aligned our study to the one by Peters et al. because it used MCSI on large numbers of ICGs for people with chronic conditions. From that study the between person standard deviation (SD) for MCSI was 6 units. Therefore, a sample-size calculation for a one-sample t-test aiming to demonstrate a difference of at least 2 units between mean MCSI in our data as compared to ones described in Peters et al. (power and alpha set at 0.80 and 0.05 respectively) required at least 75 ICG responses. Assuming a response rate of 30% (Peters et al. had 37%) meant we aimed to post 250 questionnaire packs.

Our secondary aims were to compare MCSI between ICGs of patients with and without advanced VF loss, and then to explore the association between MCSI and worsening COAG as measured by VF loss corrected for other measures such as, for example, sex, age and self-reported general health (EQ5D). Two-sample t-tests (assumed unequal variances) were used to compare means and Chi-square tests were used for categorical values. Associations were explored with Pearson correlation coefficients and a generalised linear model to correct for covariance. A value of 0.05 was used for statistical significance. Analysis was done in SPSS Statistics 23 (IBM Corp., Somers, NY) and in R (R Foundation for Statistical Computing, Vienna, Austria).

## Results

We sent invitations to 243 patients, falling short of enriching our sample with our target of inviting 50 patients with advanced COAG (n=39); finding eligible patients fulfilling the advanced VF criteria with preserved VA or not having other ocular pathology was problematic. One-hundred and sixteen (48%) patients responded. Median (interquartile range [IQR]) time period between a questionnaire pack being posted and returned was 14 (7, 25) days.

Mean (SD) age of the patients who responded (n=116) to the postal survey was 73 (10). Mean (SD) better eye MD (BEMD) of the patients who responded was -3.7 (6.4). Nine patients returned questionnaires declining to take part; two other patients were not analysed: on checking data entry of the clinical record one was found not to satisfy the inclusion criteria for VA and the other had too many missing items to be analysed meaningfully. This left 105 patients for data analysis.

Only 38 (36%) of the 105 patients analysed had an informal caregiver (ICG). These patients represent just 16% of the total of n=243 contacted, a value lower than we anticipated in our sample size calculations (30%) perhaps reflecting that most people in glaucoma clinics do not consider their condition warrants an ICG. This in itself is an important finding in relation to the conditions like PD and MS investigated by Peters et al. [6] because in that study response rates were higher.

A participant stating that they had an ICG might be related to whether they are married or have a partner. For example, in the patients with an ICG, 87% (33/38) self-reported they were married or in a committed relationship as opposed to being single, divorced, widowed or separated; in contrast this proportion was 60% (40/67) in the patients who did not have an ICG and the difference was statistically significant (p=0.004). Percentage of male participants with and without an ICG was 47% (18/38) and 55% (37/67) respectively; these values were not significantly different (p=0.439)

Our primary outcome for the study was Mean (SD) MCSI; this was 2.4 (3.4) in the 38 ICGs who completed the questionnaire (95% CI: 1.3, 3.6). This value was overwhelmingly statistically different ( $p<0.001$ , one-sample t-test) from the mean value of ~11 reported in ICGs for people with MS and PD in Peters et al. Moreover, nearly one-half ( $n=18$ ; 47%) of our sample of ICG respondents returned a MCSI of zero (indicating no ICG strain, responding negatively to all 13 items). Furthermore, only three ICGs recorded a MCSI  $>7$ , a value that some studies have described as meaningful caregiver strain. Taken together these results suggest ICG strain in COAG, as measured by MCSI, is negligible for most of the ICGs of glaucoma patients.

Mean (SD) best eye MD in patients with ( $n=38$ ) and without ( $n=67$ ) an ICG was -6.9 (9.1) dB and -2.1 (4.0) dB respectively; these values are statistically different ( $p=0.004$ ) hinting ICG strain increases with worsening VF loss. Moreover, percentage of patients with an ICG was much higher in patients with advanced VF loss (82%; 9/11) when compared to those with non-advanced VF loss (31%; 29/94) and this difference was statistically significant ( $p=0.001$ ). To further highlight this effect of ICG strain being inflated in advanced COAG, Table 1 gives the patient participant and ICG response stratified by our measure of COAG severity. For example, ICG mean (SD) MCSI was much worse when the patient had advanced VF loss (5.6 [4.9]). The three ICGs with MCSI  $> 7$  were for patients advanced VF loss too; this is noteworthy. There was no real evidence to suggest that the sex and age profile, or number of co-morbidities, of the two groups of patients were different. Yet patients with advanced VF loss, and their ICGs, had worse self-reported general health (EQ5D) compared to the others in the clinic and their respective ICGs.

**TABLE 1**

Comparison between patients with and without advanced VF loss and their respective ICG responses. Means with standard deviations (p-value for two-sample test [unequal variances]) and numbers with percentages (p value for Chi-square test) are given for the measurements and categorical values respectively. (An asterisk denotes statistical significance at  $p < 0.05$ .)

	Patients (n=9) with advanced VF loss	Patients (n=29) with non-advanced loss	p-value
Patient age (years)	78 (9)	72 (7)	0.077
Patient: female	5 (56%)	15 (52%)	0.841
Better eye mean deviation dB	-21.5 (6.1)	-2.4 (3.2)	<0.001*
Worse eye mean deviation dB	-26.5 (4.9)	-6.8 (5.3)	<0.001*
Patient: EQ5D score	0.66 (0.21)	0.87(0.15)	0.018*
Patient: Number of co-morbidities	1.9 (2.8)	1.5 (1.4)	0.690
<b>Modified Care Strain Index (MCSI)</b>	<b>5.6 (4.9)</b>	<b>1.5 (2.2)</b>	<b>0.040*</b>
Informal caregiver (ICG): number of females	5 (56%)	13 (45%)	0.573
Informal caregiver (ICG) : EQ5D score	0.77 (0.07)	0.91 (0.12)	<0.001*

Associations of measured variables with worsening MCSI in the 38 patients with ICGs are shown in Table 2.

Worsening VF and poorer self-reported general health (EQ5D) of the patient were highly associated with worsening ICG MCSI. This analysis was exploratory because our study was not powered for this. Still, no other variables had a statistically significant association with MCSI. Given the influence of patient EQ5D we

returned to our comparison of mean ICG MCSI between the patients with advanced (n=9) and non-advanced VF loss (n=29) using a general linear model (sometimes referred to as ANCOVA). After controlling for EQ5D as a covariate the difference in MCSI between the two groups still remained statistically significant ( $p=0.035$  vs  $p=0.001$  [unadjusted with equal variances assumed]) but the effect diminished with a mean (95% CI) difference in MCSI of 2.7 (0.2, 5.2) reduced from 4.1 (1.8, 6.4) (unadjusted). This analysis still suggests having advanced VF loss inflates ICG strain but in our data this is partly explained by the same patients having a co-varying worse self-reported general health. Of course, worse general health may or may not be related to having advanced VF loss, but this cannot be untangled with our data.

**TABLE 2**

Pearson correlation coefficients for different measured variables against MCSI in 38 patients with ICGs. (An asterisk denotes statistical significance at  $p<0.05$ .)

	Correlation coefficient (r)	p-value
Patient age (years)	+ 0.11	0.499
Better eye mean deviation dB	- 0.46	0.003*
Worse eye mean deviation dB	- 0.62	<0.001*
Patient: EQ5D score	- 0.53	0.001*
Patient: Number of co-morbidities	+ 0.31	0.063
Informal caregiver (ICG) : EQ5D score	- 0.26	0.113

MCSI items (questions) with the 38 ICG's responses are given in Table 3. One third of ICGs have at least sometimes made changes in personal plans because of their caregiving. Other relatively more common

strains surrounded work adjustments and less time for other family members. MCSI items referring to disturbed sleep, physical strain and a feeling of being 'overwhelmed' were completely rejected by all but a few ICGs.

**TABLE 3**

The 13 items from the Modified Care Strain index questionnaire ranked by the frequency of responses by the informal caregivers (ICGs). The top and bottom item in the table represent the item cited as the most common and least common strain experienced by the ICGs respectively. The numbers are rounded whole percent of the n=38 ICGS.

	Not at all	Sometimes	Regularly
There have been changes in personal plans because of my caregiving	66	31	3
There have been work adjustments because of my caregiving	76	16	8
Caregiving is confining/restricting	74	26	0
There have been other demands on my time (e.g. other family members need me) which I have been unable to deal with	76	24	0
It is upsetting to find the person I care for has changed so much from his/her former self	79	18	3
There have been family adjustments because of my caregiving	82	18	0
Caregiving is inconvenient	84	16	0
There have been emotional adjustments because of my caregiving	87	10	3
My caregiving is a financial strain	87	13	0
Some behaviour is upsetting (the person I care for has upsetting behaviours)	89	8	3
My sleep is disturbed by my caregiving	89	11	0

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Caregiving is a physical strain	92	8	0
I feel completely overwhelmed by my caregiving	92	8	0

Some other results from our sample of participants are worth noting. Nearly all patients (98%; 103/105) were Caucasian and 38% (40/105) self-reported being educated to degree level or higher. In our sample of 38 ICGs there were roughly equal numbers of men (n=18) and women (n=20); mean (SD) MCSI was similar (p=0.606) for men (2.1[3.6]) and women (2.7 [3.4]) too.

**Discussion**

We used a cross-sectional postal survey to illicit a measure of ICG strain for glaucoma patients in a single clinic in England. Patients were selected consecutively but the sample was enriched with a number of patients with advanced VF loss. Only 36% of patients who responded felt they had an ICG and in these, caregiver strain as measured by a standardised instrument (MCSI) was negligible. Although, in a subset of patients with advanced VF loss in both eyes, but preserved VA and no other ocular comorbidity, the ICGs response on MCSI was considerably inflated.

Results from this study represent new knowledge about ICG strain in glaucoma patients. Our data might be useful for clinicians and practitioners who may not have considered ICG in COAG before. A raised awareness is useful because there is evidence that ICGs who are given adequate support do not experience as much strain [10]. Moreover, our data might be useful for targeting patients who need extra support and also health economic models for glaucoma care [24].

Comparing MCSI values between different conditions seems attractive but is fraught with issues because of the different sampling and methodology used in different studies. For example, MCSI (not the modified version) >7 has been reported in 36% of ICGs of people recovering from hip fracture surgery [25], 15% of ICGs of people with adult cancer [26] and 24% of ICGs of people with mild relapsing-remitting MS [27]. In contrast we only had three ICGs with MCSI >7; this could be reported as 3/105 (3%) of people who were contacted/replied, or 3/38 (8%) of ICGs analysed or 3/9 (33%) of the people with advanced COAG; these different figures illustrate how sampling can affect results. We aligned our results to Peters et al. [6] but even their study had different methodology to ours. Still, for our primary outcome, mean MCSI for ICGs of patients in glaucoma clinics was considerably lower than values estimated by Peters et al. for MS and PD.

Greater ICG strain being related to worse VFs is another novel finding of our study; the association was true in the least and most affected eye. Mean MCSI was three times larger in our sample of patients with



advanced VF loss compared to other patients in the clinic; this co-varied by the patients self-reported general health (EQ5D) but the effect remained after statistically correcting for this. This result is unsurprising because studies have indicated a rapid decline in vision related quality of life in COAG as both eyes progress to end stage VF loss [28, 29] and this likely reflects the greater help these people need. Of course, our findings add to the evidence that halting VF progression is a clinical imperative, not just for the patient but also for the wellbeing of the ICG of a patient. A longitudinal study would be needed to explore how ICG strain increases as COAG progresses in an individual and this could untangle the effect from worsening of general health.

ICG strain in another age-related eye condition, AMD, has been explored but making comparison with these studies is also tricky. For example, a study specifically assessed people on ranibizumab (injection) therapy for neovascular AMD and found it was associated with significant ICG strain [14]. Other studies have highlighted ICG strain in AMD but none sampled consecutively from people in clinics nor used MCSI, so it is difficult to make comparisons [13, 15]. A large multicentre cross-sectional study conducted in Portugal demonstrated visual impairment, defined as worse than 0.30 logMAR (6/12) in the better seeing eye, incurs ICG strain [30]. Our results from patients with advanced VF loss add to this knowledge because they had inflated ICG but, because of our study design, their VA was better than 6/12.

There are good explanations for why ICG strain was insignificant in the majority of our sample of patients. Many of these patients are receiving treatment for a condition that is almost always asymptomatic until advanced in nature. In addition, patients had relatively preserved VA and no other ocular morbidity. In addition, although MCSI is widely used it is unlikely to capture specific ICG strain for people with COAG. For example, it was obvious that some MCSI items (Table 3), like care being physically draining, were rejected. Analogous to this issue is the debate about items within patient reported outcome measures (PROMs) that are not glaucoma specific and how they might, for example, be insensitive to glaucoma progression [31, 32]. Investigating the specific aspects of ICG strain in COAG, with a view to the development of a condition specific measure would be a useful area for future work.

We speculate there may be ICG strain in COAG around the different treatments (drops/surgery) and this could be the subject of future work. Other idiosyncratic ICG strains for COAG might include the psychological burden of having a potentially blinding condition or loss of visual function that might restrict mobility or remove a driving licence. We know patients are very concerned about the latter [33] and this would likely impact on their ICG too. Qualitative analysis of interviews with patients and their ICGs could pinpoint these strains; this is a subject of further work by our lab. In turn, this research could lead to development of a simple COAG specific instrument that could be administered in a clinic to detect if there was a ‘silent’ developing ICG strain. Others have discussed the importance of identifying a *precipice* when patients lose self-medicating capability, and this might be identifiable with an appropriate instrument for the ICG [34].

Other results from our study are worth discussing. Any postal survey will suffer from non-response. Our main findings are likely unaffected by this but ICG strain could be a little worse if everyone in the clinic was captured given the association of MCSI with disease severity. The high number of patients who declared not to have an ICG is interesting too. This might suggest that patients do not consider their COAG warrants an ICG. Yet we also found a strong link between having an ICG and being married or having a partner. In turn this highlights the importance of identifying patients who may be socially isolated or living on their own. Moreover, in our data we did not observe differences in the sex profile of the ICGs, with men and women reporting the same level of ICG strain. This contradicts studies where ICG strain has been thought to be something that affects women more than men [8, 9].

Our study had several strengths. We took advantage of a widely used, standardised instrument. In addition, our sampling was performed consecutively, and we measured other variables allowing for an analysis that corrected for covariates. At the same time our study has several limitations. We only sampled people from one centre; the patients were nearly all Caucasian and education levels were relatively high. (Some studies have indicated that there may be cultural and ethnic differences in the experience of ICG strain [35].) VF records were extracted from an EMR and, although unlikely, may have changed in the maximum six-month

period before a participant responded. Moreover, our study was only cross-sectional, relied on self-report and could only examine associations. Furthermore, a larger sample and conducting the study across more centres would have improved the generalisability of our results.

In conclusion, our study is novel in assessing ICG strain in patients from a glaucoma clinic. We conclude that ICG strain in the great majority of these patients is largely negligible but, importantly, it worsens as disease severity worsens. Patients with advanced VF loss in both eyes have considerably inflated ICG strain although some of this might be explained by worsening general health in these people too. Further work should be done to improve our understanding of the specific nuances of ICG in relation to COAG.

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