**QUESTION**

Dear Editor,

reading the article Psychological dynamics in glaucoma by Navarra (Ophthalmologist) and Cardella and Sances (Psychologists) [IROO 2015;1:9-24], some questions arise that could be discussed for an empowering of the context and to point out the necessity to open a broad space for the interaction between Medical Doctor and Psychologist. The foresight is to intercept the patient’s mood and “adaptation/acceptance” of a chronic drug-dependent disease, in order to better understand how to communicate with the patient and encourage him/her to find the self-motivation to reach the best compliance/adherence/therapeutic alliance. The impact of a cancer diagnosis is well established and many rules are acquired; while in Ophthalmology very few papers cover the field. Usually some psychological studies appear at the beginning of a new technique affirmation (IOLs for cataract surgery and aphakia rehabilitation; adjustable sutures for strabismus; face and skin rejuvenation, blepharoplasty at the menopausal years) while they are forgotten after the common

**DOMANDA**

Spett.le Editore,

leggendo l’articolo Psychological dynamics in glaucoma di Navarra (Oculista), Cartella e Sances (Psicologi) [IROO 2015;1:9-24], sorgono alcune questioni al fine di migliorare il contesto ed evidenziare la necessità di un largo spazio d’interazione fra il Medico e lo Psicologo. L’obiettivo riguarda l’intercettazione del “mood” del paziente e l’adattamento/accettazione di una malattia cronica farmaco-dipendente, al fine di comprendere meglio come comunicare con il paziente ed incoraggiarlo a trovare l’auto-motivazione per raggiungere la miglior compliance/aderenza/alleanza terapeutica. L’impatto psicologico di una diagnosi di cancro è ben definito e molte regole sono date per acquisite, mentre pochi articoli riguardano l’argomento in Oculistica. Comunemente alcuni studi psicologici appaiono all’affermarsi di una nuova tecnica (IOLs per la chirurgia della cataratta e la riabilitazione dell’afachia; suture aggiustabili per lo strabismo; ringiovanimento facciale e della pelle, blefaroplastica negli anni menopausali), mentre vengono a mancare dopo l’accettazione e la diffusione della stessa. Per questa ragione, la discussione su questo argomento è necessaria per
acceptance. For this reason, to discuss this subject it is mandatory to clarify some points of the paper. Primarily the form of Italian language should have been improved because an uncorrected Italian could make for a loss of credibility to the text read by patients who wish to inform themselves on a problem involving their health. While the Authors seem to have restricted the recruitment for “Glaucoma” only to POAG (primary open-angle glaucoma) patients, a subjective and sintomatologically silent disease that implies a reduced perception of the disease itself, an assumption of the study project, therefore the exclusion criteria could be deductible, even though unexplained. Although the questionnaire requests the patient to refer his/her emotions in separate moments – at the first diagnosis communication, in relation with the pathology itself and the therapy dependence, and thirdly during the patient-doctor acquaintance – the interference of drugs in patient’s lifestyle is also to be considered for data interpretation. All of the 23 patients were undergoing mono or combined topical treatment: beta-blockers can induce psychosis, sexual dysfunction, area Celsi, xerophthalmia and obviously asthma; prostaglandins analogues can induce exacerbation of angor or angina, headache, jaws-dryness, bad taste; CAI (carbonic anhydrase inhibitors) can induce irritability, depression, libido impairment and confusion. All these adverse effects can interfere with the patient’s approach to the (unreported) submitted questionnaire, inadvertently changing his/her lifestyle and self-perception, together with the drug dependence. No information about those items are reported. Unfortunately, the interesting concept of “adaptation/acceptance” is only introduced but not further developed in its psychological meanings, that could lead to a positive social learning about the disease itself and how to control its compliance through a familiar support as happens, for example,
with familiar diseases (which glaucoma is indeed) where a correct mediation process or therapeutic journey should be planned: this would be the “therapeutic alliance” of Bordin⁵ (i.e., trust, reciprocity and shared target) although the asymmetry of the patient/doctor relation could introduce an asymmetric communicative relationship, due to the necessarily different status and role according to Watzlawick⁶. For this reason, the proposal of Veatch⁷ for “The Patient as a partner” as ethical balance: “the patient is neither passive subject to be helped by father-like figures nor mere material from whom we may obtain socially useful information. It is not enough that the patient be fully informed of, and consent to, the risks. Instead, he or she is a partner in the research [and therapy, we should add], and that entails an understanding and approval of its purposes as well as its risks”. This approach would have helped not only in the relatively few cases (2/23) of the so called emotional black-out, that the Authors charge to an inadequate feeling of the Ophthalmologist inducing the patient failure, but also in reducing both the psychological reactance (1/23) and the denial phenomenon (1/23). Moreover they assume that the Ophthalmologist is rarely prone to identify the patient’s so called “white-coat syndrome” or the phenomenon of “social desirability” (the desire to avoid being judged unfavourably by the doctor), that mask the not-compliant behaviour, resulting in an unexplained worsening of control parameters (i.e. the tonometric curve/visual field/perimetric indices/PERG/PERG-PEV ratio for retino-cortical time (RCT)/RNFL decrease). This could induce continuous therapy modification, confusional therapeutic protocols and even a proposal for an early surgery. Both the perception of doctor competence and self-confidence and the doctor-patient relationship characterized by warmth, reassurance and willingness to listen, while interfering with the patient’s emotional approach to the disease, would terapeutico deve essere pianificato: si dovrebbe tendere a realizzare la “alleanza terapeutica” di Bordin⁵ (ovvero fiducia, reciprocità ed obiettivo condiviso), benché la differente posizione della relazione paziente-dottore possa introdurre una relazione comunicativa asimmetrica, dovuta allo status ed al ruolo necessariamente differente, secondo Watzlawick⁶. Per questa ragione, la proposta di Veatch⁷ di considerare il “Paziente come partner” assume un bilanciamento etico: “il paziente non è né soggetto passivo che figure paterne debbano aiutare né mero materiale dal quale ottenere informazioni socialmente utili. Non è abbastanza che il paziente sia completamente informato dei rischi, ed acconsenta agli stessi. Invece, egli è partner della ricerca [e terapia, aggiungergene,] ciò comporta la comprensione ed approvazione delle sue finalità così come dei suoi rischi”. Questo approccio avrebbe aiutato non solo nei relativamente pochi casi (2/23) del cosiddetto blackout emotionale, che gli Autori addebitano ad un inadeguato rapporto emotivo dell'Oculista che causa il fallimento del paziente, ma anche nella riduzione della reattanza psicologica (1/23) e del fenomeno della negazione (1/23). Inoltre gli AA. assumono che l’Oculista sia raramente pronò all’identificazione della cosiddetta “sindrome del camice bianco” da parte del paziente o al fenomeno della “desiderabilità sociale” (il desiderio di evitare il giudizio sfavorevole del dottore), che nasconderanno il comportamento non-compliant, risultando in un inspiegato peggioramento dei parametri di controllo (ad esempio curva tonometrica/campo visivo/indici perimetrici/PERG/PERG-PEV ratio for retino-cortical time (RCT)/riduzione RNFL). Questo può comportare un continuo aggiustamento della terapia, protocolli terapeutici confusionali ed anche la proposta per una chirurgia anticipata. Sia la percezione della competenza e dell’auto-considerazione professionale del medico sia una relazione dottore-paziente caratterizzata da calore, rassicurazione e disponibilità all’ascoito, mentre da un lato interferiscono con l’approccio emotionale del paziente alla malattia,
improve or reduce the future compliance justifying the coaching Psychologist to the consultant Ophthalmologist. Lastly, it seems like a weak point to not have evaluated the moment of the diagnosis communication as a way for personal improvement of the patient, and change of the mental span towards a wider opening. To adapt themselves to a chronic disease with the consequences of adaptation and dependence to an usually lifelong therapy, and therefore to an “ego de-strengthening”, needs a total re-definition of the patient’s identity. For these reasons, the role of the Psychologist/Familiar Mediator, a new professional profile in the glaucoma care, should be emphasized as a new opportunity to offer a providential support to the patient directly in the phase of diagnosis/prognosis and therapy communication jointly with the Ophthalmologist, and this would be a major strength of the proposed paper, even though the statistical power itself is really weak, as are some of the previous papers whose questionnaires are quoted by the Authors as “not entirely reliable”. Furthermore, having to confront with problems like depression syndrome, negation and quality of life level, a standardized personality test together with a Quality of Life (QoL) scale and a questionnaire on the familiar perception of the illness would have well integrated the Material and Methods to verify how much personality, temperament and behaviour could influence the patient’s reaction to the glaucoma diagnosis and subsequently the compliance/alliance with the prescribed therapy. This will open the way to the distribution of this joint methodology approach through medical trainings and public educational campaigns.

Summary: the consultancy of a Psychologist/Familiar Mediator in support of the Ophthalmologist’s work during the first diagnostic assessment of glaucoma (POAG) would improve the future therapeutic alliance possibly overcoming the white-

dall’altro potrebbero migliorare o ridurre la compliance futura giustificando l’affiancamento all’Oculista dello Psicologo nella valutazione e nel trattamento del paziente. Infine, un punto debole sembra essere il non avere considerato il momento della comunicazione della diagnosi come un momento di miglioramento personale del paziente e un cambiamento della mentalità verso una maggior apertura, cioè equilibrata accettazione. Per adattare se stessi ad una malattia cronica con le conseguenti necessità di adeguamento e dipendenza da una terapia che dura solitamente per tutta la vita, e quindi ad un “de-potenziamento” dell’ego, è necessaria una completa ridefinizione dell’identità del paziente. Per queste ragioni, il ruolo dello Psicologo/Mediatore Familiare, un profilo professionale non presente nella cura del glaucoma, dovrebbe essere enfatizzato come una nuova opportunità di fornire un supporto provvidenziale al paziente direttamente nella fase di diagnosi/prognosi e di comunicazione della terapia insieme all’Oculista; questa proposta potrebbe essere uno dei principali punti di forza dello studio presentato, anche se il potere statistico dell’articolo è molto debole, come alcuni dei lavori precedenti i cui questionari sono citati dagli Autori come “non completamente affidabili”. Inoltre, dovendosi confrontare con problemi come la sindrome depressiva, la negazione ed il livello di qualità della vita, l’utilizzo di un test di personalità standardizzato insieme con una scala sulla Quality of Life (QoL) ed un questionario sulla percezione familiare della malattia avrebbero ben integrato la sezione Materiali e Metodi per verificare come personalità, temperamento e comportamento possano influenzare la reazione del paziente alla diagnosi di glaucoma e conseguentemente alla compliance/alleanza con la terapia prescritta. Si aprirà quindi la via alla diffusione di un approccio congiunto alla metodologia attraverso una adeguata e integrata formazione medica e campagne di educazione e comunicazione pubbliche.

Sommaio: la consulenza di uno Psicologo/Mediatore Familiare a supporto del lavoro
coat syndrome, the emotional black-out, the psychological reactance and denial phenomenon while increasing the patient/doctor/familiar relationship and providing a positive social learning about the disease. del’Oculista durante l’inquadramento diagnostico e terapeutico del glaucoma (POAG) migliorerà la successiva alleanza terapeutica, superando potenzialmente la sindrome da camice bianco, il black-out emozionale, la reattanza psicologica ed il fenomeno della negazione mentre contemporaneamente migliorerà la relazione dottore/paziente/famiglia e fornirà un social learning positivo per la malattia.

Keywords:
glaucoma, Psychologist, Familiar Mediator, compliance, therapeutic alliance, social learning

Parole chiave:
glaucoma, Psicologo, Mediatore Familiare, compliance, alleanza terapeutica, social learning

References
DINAMICHE PSICOLOGICHE NEL GLAUCOMA: OSSERVAZIONI E COMMENTO

PSYCHOLOGICAL DYNAMICS IN GLAUCOMA: EXTENDED REMARKS

Chiara Sances, Antonietta Navarra, Stefano Cardella

ANSWER

First of all, we would like to thank our colleagues for the interest they have shown: raising ophthalmologists' concern regarding the importance of the doctor-patient communication in glaucoma was in fact one of our main objectives. For this reason, it seems right to gloss over the objection the authors make concerning the presentation of the Italian language, which does not contain anything of merit, as it appears generic on the one hand and of little relevance regarding the reasons given on the other.

As you have pointed out, there are, in fact, very few studies that have analysed the psychological dimension of these patients in-depth. The majority of works found in the literature has employed self-administered questionnaires, and these have been associated with or replaced by interviews with a psychologist, as we did in our study, only very rarely.

We deliberately preferred this approach, because it allowed us to evaluate each single patient in depth and in a qualified manner.

As concerns the choice to only insert patients suffering from POAG, this was made in order to obtain a sample as homogenous as possible, which we felt was appropriate. An accurate medical history was made to rule out any serious drug-related side effects and all patients with associated psychiatric disorders were excluded.

It is worth underlining that some side effects, unfortunately, are an integral part of the treatment of glaucoma and therefore are impossible to exclude; an example is given by the strong hyperaemia caused by prostaglandins. The colleagues from the Universities of Chieti and Ferrara have rightly underlined how much the treatment may affect the patient's lifestyle, and we would add, that of his family. This is why some of

RISPOSTA

Innanzitutto vogliamo ringraziare i colleghi per l'interesse dimostrato: sensibilizzare infatti gli oftalmologi sull'importanza della comunicazione medico-paziente nel glaucoma era uno dei nostri principali obiettivi. Per questo ci sembra giusto sorvolare sull'appunto che gli autori fanno relativamente alle questioni di forma dell'italiano, che non contiene alcun elemento di merito, risultando generico da un lato e poco rilevante riguardo le motivazioni addotte dall'altro.

Come avete sottolineato, esistono, in effetti, ben pochi studi che hanno approfondito la sfera psicologica di questi pazienti. Nella maggior parte dei lavori trovati in letteratura, sono stati utilizzati dei questionari autosomministrati e solo molto raramente questi sono stati associati o sostituiti da colloqui con uno psicologo, come abbiamo fatto nel nostro studio.

Abbiamo preferito volutamente tale approccio, perché ci ha permesso di valutare in modo approfondito e qualificato ogni singolo paziente.

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the questions in the second part of the structured interview, whose purpose was to allow the patient to give his/her experience and to talk about himself/herself in relation to the “glaucoma disease”, were designed precisely to investigate the relationship with the drug therapy in the short and the long-term*.

These are the questions investigating these aspects:
• Which are the most annoying or limiting aspects of the therapy you are following?
• Are they the same for you and for those around you?
• How much do they influence your quality of life from 1 to 10? (Indicate 1 in the event of no effect and 10 if they greatly affect your quality of life).
• How much do they influence the quality of life of those around you from 1 to 10? (Indicate 1 in the event of no effect and 10 if they greatly affect their quality of life).

In particular, we decided to assess the impact of the disease and of the related treatments through the use of open-ended questions rather than by administering a QL questionnaire, because of their inherent flexibility, a feature that we found preferable rather than comparing QL questionnaires in an exploratory study such as ours. The lack of statistically significant data in the answers and the frequent use of “normalisation” gimmicks by the patients (their frequent answers were “no effect”, “no change”, “they have no effect”), in fact represented an important feedback which guided us and allowed us to put into place a few “adjustments” to the chosen and used methodology.

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as sexual dysfunctions, decreased libido, may be ascribed to the interview setting, which envisages exposure to a "stranger" unlike the status of anonymity guaranteed by a self-administered questionnaire.

Given the peculiarities of the disease, we believe that acceptance of the glaucoma by the patient is very difficult and complex and that the moment of communication is very important and sensitive; we think it is risky to consider it as a moment of improvement, both because of the reports by our patients (almost all experienced this negatively), and because of the features of the disease itself (an asymptomatic disease in a high percentage of cases until the moment of its diagnosis, whose subsequent therapy worsens symptoms and the patient’s quality of life instead of improving it).

Wishing to examine the matter more in depth, the point made relating to “not having considered the moment of communication of the diagnosis as a step for the patient's personal improvement and a change towards a more open mind-set, i.e., a balanced acceptance”, mainly appears to be the result of a misunderstanding born from using different perspectives. Therefore, it is obviously necessary to specify these. Contrary to what the authors of the comments understood, and despite the significant data, we do not in fact believe a priori that the encounter with the disease may not be favourably resolved by the person on the inside, although it involves having to face the sorrow of a severe narcissistic wound (an “ego de-strengthening” in the words of the authors). We simply avoided using terms which were implicitly or explicitly evaluative of the change as we consider them risky and misleading in their implicit standard sense. The adaptation required by the awareness of suffering from a chronic disease, can indeed be surely assessed in terms of social desirability, i.e. on the basis of standards sufficiently shared by the community (and by the physician who is also a member of it), which establish what constitutes an improvement and what a deterioration, what is a balanced acceptance (which is the perspective which the authors of the comments implicitly make theirs, we do not know with what degree of awareness). However, we
believe that an individual person can only be helped to find his/her own adjustment, i.e. the best one for himself or herself, partly irrespective of whether this is in line or not with society’s desiderata. We emphasise this ‘partly’ as we are aware that both the patient and his/her physician live within the same community, and certainly cannot completely set themselves apart from its rules. However, it should be noted that, where such rules should tend to gain the upper hand in rigidly defining and narrowing down choices and the assessment of the doctor-patient relationship, they would end up by heavily interfering with the listening, understanding and mutual modulation skills which underlie all effective therapeutic relationships. Precisely in this sense, one of the roles which the psychologist may carry out when flanking the doctor is to promote the latter’s ability to remain open towards the patient’s solutions and adaptations, although these can sometimes seem incomplete and unsatisfactory, rather than to reject them, which threatens to undermine the therapeutic relationship.

This interchange is based on the different perception that a doctor and a psychologist have of their role. If on the one hand, the explicit and implicit rules of the professional educational process teach the former to stand as the patient’s safe guide, as the one who has the knowledge (who knows what is good for the patient, what makes him/her better, what a balanced adaptation is etc.), on the other, the latter is specifically taught to step back from his/her alleged knowledge and preconceptions in order to allow room for listening to the patient’s subjective truth.

The subject is naturally wide-ranging and complex and has been debated for some time, for example in the large sector of narrative medicine and in that of counselling (Charon R. 2006, Kleinmann A 1988, Bert and Quadrino 2002), but it is worth picking it up again here in order to emphasise how the meeting, confrontation and integration of these two perspectives would be highly desirable, particularly when treating chronic diseases, such as glaucoma, which require a solid and lasting therapeutic relationship.