PSICOLOGIA CLINICA

dott.ssa Paoletta Florio psicologa-psicoterapeuta



ALLEANZA TERAPEUTICA

- cos'è?
- perché è utile?
- da chi dipende?
- come si favorisce?

DEFINIZIONE

<u>alleanza terapeutica</u>: il legame tra paziente e operatore e il reciproco accordo circa gli obiettivi del cambiamento e le azioni utili per realizzare tali obiettivi (Bordin, 1979)



- perché è utile?
- da chi dipende?
- come si favorisce?

FUNZIONI

- fiducia nel medico = soddisfazione + comunicazione + competenza + rispetto della privacy
- la fiducia nel medico correla positivamente con misure self-report relative a:
 - stato di salute (Kao et al., 1998)
 - sintomatologia (Thom et al., 2002)
 - qualità di vita globale (Preau et al., 2004)



FUNZIONI

fiducia \rightarrow migliore aspettativa e migliore auto-efficacia \rightarrow migliore adesione al trattamento \rightarrow migliori esiti:

- misure oggettive:
 - indice di massa corporea
 - glicemia
 - trigliceridi
 - complicazioni correlate al diabete
- misure self-report:
 - salute fisica
 - salute mentale

(Lee e Lin, 2009)



FUNZIONI

- è un buon predittore degli esiti del trattamento
- favorisce l'aderenza al trattamento
- influenza i sintomi depressivi
- facilita il coinvolgimento nel percorso
- incrementa il livello di soddisfazione

(Hall et al., 2010; Bright 2015, Kayes et al., 2015)

- da chi dipende?
- come si favorisce?

DA CHI DIPENDE?

- <u>paziente</u>: si trova in condizione di bisogno e, talvolta, le caratteristiche stesse della sua patologia gli rendono difficile il compito di relazionarsi in modo adeguato e costruttivo
- <u>operatore</u>: si trova nella posizione di poter favorire la costruzione di una fruttuosa alleanza terapeutica e dovrebbe possedere le competenze necessarie
- come si favorisce?

COME SI FAVORISCE?



Pergamon



Clinical Psychology Review 23 (2003) 1-33

A review of therapist characteristics and techniques positively impacting the therapeutic alliance

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Received 15 March 2001; received in revised form 26 July 2001; accepted 2 May 2002

Abstract

The present review is a comprehensive examination of the therapist's personal attributes and insession activities that positively influence the therapeutic alliance from a broad range of psychotherapy perspectives. Therapist's personal attributes such as being flexible, honest, respectful, trustworthy, confident, warm, interested, and open were found to contribute positively to the alliance. Therapist techniques such as exploration, reflection, noting past therapy success, accurate interpretation, facilitating the expression of affect, and attending to the patient's experience were also found to contribute positively to the alliance. This review reveals how these therapist personal qualities and techniques have a positive influence on the identification or repair of ruptures in the alliance. © 2003 Elsevier Science Ltd. All rights reserved.



ATTEGGIAMENTO DEGLI OPERATORI SANITARI COME SI FAVORISCE?

Journal of Psychiatric and Mental Health Nursing, 2012, 19, 1–7

The quality of the working alliance between chronic psychiatric patients and their case managers: process and outcomes



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COME SI FAVORISCE?

De Leeuw et al. (2012)

caratteristiche della sintomatologia del paziente che inficiano la qualità dell'alleanza terapeutica:

- ostilità
- sfiducia
- alienazione
- abilità inadeguate di adattamento
- ridotta consapevolezza di malattia

COME SI FAVORISCE?

De Leeuw et al. (2012)

caratteristiche del case manager:

- fornisce supporto pratico nelle attività di vita quotidiana
- mostra empatia
- mostra rispetto
- attenzione sia alla «parte sana» che alla «parte malata»



COME SI FAVORISCE?

Pinto et al: Communication style and therapeutic alliance

Patient-centred communication is associated with positive therapeutic alliance: a systematic review

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PUBLIC STIGMA

Never Rarely Sometimes Often Always

Because of my illness, some people avoided me

Because of my illness, I felt left out of things

Because of my illness, people avoided looking at me

I felt embarrassed about my illness

Because of my illness, some people seemed uncomfortable with me

I felt embarrassed because of my physical limitations

Because of my illness, people were unkind to me

Some people acted as though it was my fault I have this illness

PUBLIC STIGMA

CanJPsychiatry 2012;57(8):464-469

In Review

On the Self-Stigma of Mental Illness: Stages, Disclosure, and Strategies for Change

Patrick W Corrigan, PsyD1; Deepa Rao, PhD, MA2

 <u>public stigma</u>: rappresenta il pregiudizio e la discriminazione diretta ad un gruppo e si riferisce agli atteggiamenti negativi nei confronti delle persone che vengono svalutate

PUBLIC STIGMA

<u>stereotipi negativi</u>: caratterizzazioni (per esempio, pericolosità) delle persone che vivono certe condizioni da parte della società <u>pregiudizio</u>: emozione (per esempio, paura) provata da chi condivide lo stereotipo negativo <u>discriminazione</u>: comportamento che deriva dal pregiudizio; si manifesta in tre modi:

- perdita di opportunità (per esempio, non viene affittato un appartamento ad una persona con problemi di salute mentale)
- **COErcizione** (per esempio, un'autorità prende decisioni per un paziente psichiatrico)
- Segregazione (istituzionalizzazione o isolamento nei contesti sociali) (Carozza, 2014)

PUBLIC STIGMA

- gli stereotipi nascono al processo di categorizzazione (Tajfel, 1969)
- categorizzazione = «processo cognitivo secondo cui gli individui ordinano mentalmente il loro mondo sociale e riducono la quantità di informazioni con cui si confrontano» (Villano, 2016)
- effetti della categorizzazione:
 - accentuazione della somiglianza intracategoriale
 - accentuazione delle differenze intercategoriali
- la sola divisione in gruppi può creare un effetto di omogeneità dell'outgroup (Quattrone e Jones, 1980) e un favoritismo per l'ingroup (Tajfel, 1969)

PUBLIC STIGMA

l'esperimento della Robber's Cave (Sherif e Sherif, 1961)

1. formazione dei gruppi: attività piacevoli

introduzione di condizioni competitive: partecipazione
a competizioni sportive a gruppi con premio finale per il
gruppo vincitore e i singoli membri

 \rightarrow le aquile e i serpenti

3. riduzione della conflittualità

PUBLIC STIGMA E SELF STIGMA

CanJPsychiatry 2012;57(8):464-469

In Review

On the Self-Stigma of Mental Illness: Stages, Disclosure, and Strategies for Change

Patrick W Corrigan, PsyD¹; Deepa Rao, PhD, MA²

- <u>public stigma</u>: rappresenta il pregiudizio e la discriminazione diretta ad un gruppo e si riferisce agli atteggiamenti negativi nei confronti delle persone che vengono svalutate
- <u>self-stigma</u>: internalizzazione degli atteggiamenti pubblici

Stigma is a complex phenomenon due to the interaction between a context and a subject who receives a devaluating mark (Maffoni et al., 2017)

PUBLIC STIGMA E SELF STIGMA

il processo di auto-stigmatizzazione richiede:

- consapevolezza della discriminazione subita «chi ha un problema di salute mentale è pericoloso (o colpevole di essere malato e/o incompetente e/o parassita della società)»
- condivisione degli stereotipi da parte della persona malata «è vero»
- applicazione degli stereotipi a se stesso «sono pericoloso»

<u>self-stigma</u>: «sono pericoloso» «temo me stesso» «mi isolo»

PUBLIC STIGMA E SELF STIGMA

Figure 1 The stage model of self-stigma



SELF STIGMA

impatto del self-stigma:

- riduce autostima e autoefficacia (Latalova et al., 2014; Kleim et al., 2008)
- riduce la capacità/propensione di accedere ai servizi (Corrigan et al., 2009)
- ostacola il raggiungimento degli obiettivi di vita (Corrigan et al., 2009)
- riduce l'aderenza al trattamento (Kamaradova et al., 2016)
- determina esiti peggiori (Ritsher e Phelan, 2004; Tsang et al., 2010; Ociskova et al., 2014, 2015, 2016)
- riduce la qualità di vita (Holubova et al., 2016; Latalova et al., 2014)

SELF STIGMA

Journal of Mental Health, October 2008; 17(5): 482-491 informa healthcare

Perceived stigma predicts low self-efficacy and poor coping in schizophrenia

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Abstract

Background: The stigma of mental illness has been shown to be a barrier to recovery in schizophrenia. Aims: The present study aimed to examine the influence of perceived stigma on self-efficacy and the coping styles of secrecy and withdrawal over and above selected sociodemographic and clinical variables and psychopathology.

Method: Outpatients diagnosed with schizophrenia (N=127) filled in measures of perceived stigma, secrecy and withdrawal as coping modi, positive and negative symptom severity, self-efficacy, depression and insight into psychosis.

Results: Perceived stigma accounted for a significant amount of variance in secrecy and withdrawal, as well as low self-efficacy, over and above the amount of variance explained by positive and negative symptomatology, depression, insight, age and gender.

Condusion: Our findings demonstrate the negative influence of stigma perceived by persons with schizophrenia on self-efficacy and coping. Clinicians should offer guidance in functional coping with perceived stigma in order to reduce the effect of stigma on patients' lives.

SELF STIGMA

Patient Preference and Adherence

Dovepress open access to scientific and medical research

d Open Access Full Text Article

ORIGINAL RESEARCH

Connection between self-stigma, adherence to treatment, and discontinuation of medication

This article was published in the following Dove Press journal: Patient Preference and Adherence 22 July 2016 Number of times this article has been viewed

Dana Kamaradova¹ Klara Latalova¹ Jan Prasko¹ Radim Kubinek¹ Kristyna Vrbova¹ Barbora Mainerova¹ Andrea Cinculova¹ Marie Ociskova¹ Michaela Holubova² Jarmila Smoldasova¹ Anezka Tichackova¹

¹Department of Psychiatry, University Hospital Olomouc, ²Faculty of Medicine and Dentistry, Palacky University Olomouc, Olomouc, Czech Republic Introduction: Self-stigma plays a role in many areas of the patient's life. Furthermore, it also discourages therapy. The aim of our study was to examine associations between self-stigma and adherence to treatment and discontinuation of medication in patients from various diagnostic groups.

Methods: This cross-sectional study involved outpatients attending the Department of Psychiatry, University Hospital Olomouc, Czech Republic. The level of self-stigma was measured with the Internalized Stigma of Mental Illness and adherence with the Drug Attitude Inventory. The patients also anonymously filled out a demographic questionnaire which included a question asking whether they had discontinued their medication in the past.

Results: We examined data from 332 patients from six basic diagnostic categories (substance abuse disorders, schizophrenia, bipolar disorders, depressive disorders, anxiety disorders, and personality disorders). The study showed a statistically significant negative correlation between self-stigma and adherence to treatment in all diagnostic groups. Self-stigma correlated positively and adherence negatively with the severity of disorders. Another important factor affecting both variables was partnership. Self-stigma positively correlated with doses of antidepressants and adherence with doses of anxiolytics. Self-stigma also negatively correlated with education, and positively with a number of hospitalizations and number of psychiatrists visited. Adherence was further positively correlated with age and age of onset of disorders. Regression analysis showed that self-stigma was an important factor negatively influencing adherence to treatment and significantly contributing to voluntary discontinuation of drugs. The level of self-stigma did not differ between diagnostic categories. Patients suffering from schizophrenia had the lowest adherence to treatment.

Conclusion: The study showed a significant correlation between self-stigma and adherence to treatment. High levels of self-stigma are associated with discontinuation of medications without a psychiatrist's recommendation. This connection was present in all diagnostic groups. Keywords: self-stigma, adherence, discontinuation of drugs, mental disorders

SELF STIGMA

Neuropsychiatric Disease and Treatment

Dovepress open access to scientific and medical research

Open Access Full Text Article

ORIGINAL RESEARCH

Self-stigma and quality of life in patients with depressive disorder: a cross-sectional study

This article was published in the following Dove Press journal: Neuropsychiatric Disease and Treatment 19 October 2016 Number of times this article has been viewed

Michaela Holubova^{1,2} Jan Prasko¹ Marie Ociskova¹ Marketa Marackova¹ Ales Grambal¹ Milos Slepecky³

¹Department of Psychiatry, Faculty of Medicine and Dentistry, Palacky University Olomouc, University Hospital Olomouc, Olomouc, ³Department of Psychiatry, Hospital Liberec, Liberec, Czech Republic; ³Department of Psychology Sciences, Faculty of Social Science and Health Care, Constantine the Philosopher University, Nitra, Slovak Republic **Background:** Self-stigma is a maladaptive psychosocial phenomenon that can affect many areas of patients' lives and have a negative impact on their quality of life (QoL). This study explored the association between self-stigma, QoL, demographic data, and the severity of symptoms in patients with depressive disorder.

Patients and methods: Patients who met the International Classification of Diseases, 10th revision, research criteria for depressive disorder were enrolled in this cross-sectional study. All outpatients completed the following measurements: the Quality of Life Enjoyment and Satisfaction Questionnaire, the Internalized Stigma of Mental Illness Scale, demographic questionnaire, and the objective and subjective Clinical Global Impression-Severity scales that measure the severity of disorder. A total of 81 depressive disorder patients (with persistent affective disorder – dysthymia, major depressive disorder, or recurrent depressive disorder) and 43 healthy controls participated in this study.

Results: Compared with the healthy control group, a lower QoL was observed in patients with depressive disorder. The level of self-stigma correlated positively with total symptom severity score and negatively with QoL. Multiple regression analysis revealed that the overall rating of objective symptom severity and score of self-stigma were significantly associated with QoL.

Conclusion: This study suggests a lower QoL in patients with depressive disorder in comparison with healthy controls and a negative impact of self-stigma level on QoL in patients suffering from depressive disorders.

Keywords: self-stigma, quality of life, depressive disorder

SELF STIGMA

Review Article

Stigma Experienced by Parkinson's Disease Patients: A Descriptive Review of Qualitative Studies

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SELF STIGMA



SELF STIGMA

SELF STIGMA

indicatori di self-stigma:

- si perde l'identità personale, sostituita da un senso del sé definito interamente dalla malattia
- tutte le attività della vita ruotano intorno all'essere paziente psichiatrico
- si sviluppa l'alienazione dagli altri
- si perdono i precedenti ruoli sociali
- si sviluppa un'idea di sé svalutata e socialmente indesiderata

SELF STIGMA

Figure 2 A hierarchy of disclosure strategies

Social avoidance: Stay away from others so they do not have a chance to stigmatize me!

Secrecy: Go out into the world—work and go to church—but tell no one about my illness.

Selective disclosure: Tell people about my illness who seem like they will understand.

Indiscriminant disclosure: Hide it from no one.

Broadcast: Be proud. Let people know.



«la percezione che la persona ha della sua posizione nella vita nel contesto dei sistemi culturale e valoriale in cui vive e in relazione ai suoi obiettivi, alle sue aspettative, ai suoi standard e alle sue preoccupazioni. Si tratta di un concetto ampio influenzato in modo complesso dalla salute fisica, dallo stato psicologico, dal livello di indipendenza, dalle relazioni interpersonali, dalle credenze personali e dalle loro interazioni con le caratteristiche salienti dell'ambiente»

(OMS, 1994)

QUALITÀ DI VITA

QUALITÀ DI VITA CONNESSA ALLO STATO DI SALUTE

area dei sintomi fisici legati alla malattia e/o ai trattamenti: dolore, dispnea, perdita dei capelli area della funzionalità fisica: capacità di svolgere le normali attività quotidiane come cura di sé, attività lavorativa e tempo libero area dello stato emotivo: ansia, depressione, irritabilità area delle relazioni sociali: interazioni con i familiari e con

gli amici

... ma anche aspetti spirituali ed esistenziali, funzionalità sessuale, immagine corporea, soddisfazione per le cure ricevute e per la relazione medico-paziente...

QUALITÀ DI VITA

CANCRO DEL DISTRETTO TESTA-COLLO



CANCRO DEL DISTRETTO TESTA-COLLO

Danker et al. (2010) – <u>Social withdrawal after laryngectomy</u>

- 40% dei 218 pz. con LT evita le conversazioni sociali
- 70% evita di partecipare ad attività sociali
- frequente la percezione di public stigma a causa del cambiamento della voce e della presenza di una tracheostomia

CANCRO DEL DISTRETTO TESTA-COLLO

PSYCHOSOCIAL ADJUSTMENT IN HEAD AND NECK CANCER: THE IMPACT OF DISFIGUREMENT, GENDER AND SOCIAL SUPPORT

Mark R. Katz, MD, FRCPC,¹ Jonathan C. Irish, MD, MSc, FRCSC,² Gerald M. Devins, PhD, C. Psych,¹ Gary M. Rodin, MD, FRCPC,¹ Patrick J. Gullane, MB, FRCSC, FACS²

CANCRO DEL DISTRETTO TESTA-COLLO

- 1. danno estetico:
 - importanza per l'immagine di sé
 - importanza per le relazioni interpersonali
 - importanza per la comunicazione
 - altamente visibile
 - come misurarla?
- 2. <u>genere</u>: le donne incontrano maggiori difficoltà nell'adattamento alle sequele del cancro?
- 3. <u>supporto sociale</u>: la percezione del supporto sociale pare correlata ad una migliore qualità di vita
<u>risultati</u>:

- 1. livelli maggiori di depressione nelle donne e nei soggetti con più importante danno estetico
- 2. livelli maggiori di benessere psicologico in coloro che esperiscono maggiore supporto sociale
- il supporto sociale modera gli effetti del danno estetico sul benessere psicologico nella donna, ma non nell'uomo
- 4. livelli più bassi di «life happiness» nelle donne e nei soggetti con più severo danno estetico

conclusioni:

le donne sembrano più vulnerabili all'impatto del cancro del distretto testa-collo rispetto agli uomini e il loro adattamento dipende maggiormente dall'ambiente sociale

CANCRO DEL DISTRETTO TESTA-COLLO

THE IMPACT OF HEAD AND NECK CANCER AND FACIAL DISFIGUREMENT ON THE QUALITY OF LIFE OF PATIENTS AND THEIR PARTNERS

Lindsey E. Vickery, DClin Psychol,¹ Gary Latchford, PhD,² Jenny Hewison, PhD,² Maggie Bellew, PhD,¹ Tricia Feber, Dip Nursing³

- la variabile «danno estetico» ha una ridotta ripercussione sulla qualità della vita possibili interpretazioni:
- 1. il danno estetico è il prezzo da pagare per la sopravvivenza
- 2. danno estetico non così devastante
- 3. campione ridotto (chi non partecipa ha maggiori difficoltà di adattamento?)

CANCRO DEL DISTRETTO TESTA-COLLO

Acta Otolaryngol 2004; 124: 509-514

Taylor & Francis healthsciences

Elderly Patients with Head and Neck Cancer: Physical, Social and Psychological Aspects after 1 Year

WYNIA DERKS1, ROB DE LEEUW2, JACQUES WINNUBST2 and GERRIT JAN HORDIJK1

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Derks W, De Leeuw R, Winnubst J, Hordijk GJ. Elderly patients with head and neck cancer. physical, social and psychological aspects after 1 year. Acta Otolaryngol 2004 124: 509-514.

Objective—Elderly patients with head and neck cancer often receive non-standard treatment for reasons other than comorbidity. In this prospective study we investigated how elderly patients fare 1 year after treatment in comparison with their younger counterparts.

Material and Methods—Seventy patients aged 45-60 years and 51 patients aged \geq 70 years with cancer of the oral cavity, pharynx (stage II-IV) or larynx (stage III-IV) participated in the study before treatment and 1 year later. Each patient was interviewed and given a questionnaire concerning physical functioning, social contacts, depressive symptoms, satisfaction with treatment and future expectations.

Results—At 12 months, patients in both age groups reported significantly more depressive symptoms and less social support than before treatment, and their Karnofsky Performance Score was lower. However, there were no differences between elderly and younger patients. Approximately 90% of those in both age groups said that they would choose the same treatment again, and there was no age difference regarding the impact of treatment or expectations for the future.

Conclusion — This study shows that the impact of treatment on quality of life did not differ between elderly and younger patients with head and neck cancer. Therefore, standard treatment should be considered in elderly patients if no severe contraindications exist. Key words: Depression, elderly, head and neck neoplasm, quality of life, social support therapy.

QUALITY OF LIFE IN ELDERLY PATIENTS WITH HEAD AND NECK CANCER ONE YEAR AFTER DIAGNOSIS

Wynia Derks, MD,¹ Rob J. de Leeuw, PhD,² Gerrit Jan Hordijk, MD, PhD,¹ Jacques A. Winnubst, PhD²

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confermano i dati precedenti

CANCRO DEL DISTRETTO TESTA-COLLO

Acta Otolaryngol 2004 124: 231-236

Taylor & Francis
 healthsciences

REVIEW ARTICLE

Quality of Life Following Neck Dissections

SIMON N. ROGERS¹, ALFIO FERLITO², PHILLIP K. PELLITTERI³, ASHOK R. SHAHA⁴ and ALESSANDRA RINALDO²

From the ¹Department of Oral and Maxillofacial Surgery, University Hospital Aintree and Liverpool University Dental Hospital, Liverpool, UK, the Departments of Otolaryngology-Head and Neck Surgery, ²University of Udine, Udine, Italy and ³Geisinger Medical Center, Danville, Philadelphia, USA and the ⁴Head and Neck Service, Memorial Sloan-Kettering Cancer Center, New York, New York, USA

- 1. maggiore estensione della chirurgia del collo \rightarrow maggiore gravità della patologia della spalla
- 2. risparmio del nervo accessorio spinale
- 3. dolore maggiore per svuotamenti più estesi

SHOULDER AND NECK MORBIDITY IN QUALITY OF LIFE AFTER SURGERY FOR HEAD AND NECK CANCER

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riduzioni nell'abduzione e dolore localizzato alla spalla sono significativamente correlati all'esito in quattro domini:

- 1. funzionamento fisico
- 2. limitazioni dovute a problemi fisici
- 3. dolore
- 4. generale percezione della salute

CANCRO DEL DISTRETTO TESTA-COLLO

RADIATION-INDUCED XEROSTOMIA IN PATIENTS WITH HEAD AND NECK CANCER: PATHOGENESIS, IMPACT ON QUALITY OF LIFE, AND MANAGEMENT

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Support Care Cancer (2008) 16:171-179 DOI 10.1007/s00520-007-0300-5

ORIGINAL ARTICLE

The influence of xerostomia after radiotherapy on quality of life

Results of a questionnaire in head and neck cancer

Piet Dirix · Sandra Nuyts · Vincent Vander Poorten · Pierre Delaere · Walter Van den Bogaert

la xerostomia è associata a:

- 1. dolore alla bocca
- 2. incremento delle carie dentali e delle infezioni orali
- 3. difficoltà nel parlare e nel deglutire
- 4. riduzione dell'alimentazione e perdita di peso

CANCRO DEL DISTRETTO TESTA-COLLO

QUALITY OF LIFE AS PREDICTOR OF WEIGHT LOSS IN PATIENTS WITH HEAD AND NECK CANCER

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Accepted 4 November 2004

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ORIGINAL ARTICL

MALNUTRITION AND QUALITY OF LIFE IN PATIENTS TREATED FOR ORAL OR OROPHARYNGEAL CANCER

Harriët Jager-Wittenaar, RD,¹ Pieter U. Dijkstra, PT, MT, PhD,^{1,2,3} Arjan Vissink, DDS, MD, PhD,¹ Bernard F. A. M. van der Laan, MD, PhD,¹ Rob P. van Oort, DDS, PhD,¹ Jan L. N. Roodenburg, DDS, MD, PhD¹

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- perdita di peso (incidenza 35-50%) → incrementa morbilità e mortalità e riduce la tolleranza alla radioterapia e alla chemioterapia
- una perdita di peso che supera il 10% del peso in 6 mesi → malnutrizione e peggiore QOL anche a 3 anni

QUALITY OF LIFE AND ILLNESS PERCEPTIONS IN PATIENTS WITH RECENTLY DIAGNOSED HEAD AND NECK CANCER

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Apparently, it is not so much the disease itself but the way the patient perceives and responds to the disease that determines an individual's QOL.^{6,9}

Eliciting the patient's views of his or her illness offers the potential for a better understanding of (mal)adaptive response to illness and treatment and has implications for medical practice.

conclusioni:

pazienti con percezioni di malattia più negative prima del trattamento (aumentata attenzione ai sintomi, aumentata credenza rispetto alla possibilità di una recidiva, maggiore tendenza ad autocolpevolizzarsi e reazioni emozionali più forti alla malattia) hanno una più ridotta qualità di vita

Patients' views on the utility of quality of life questionnaires in head and neck cancer: a randomised trial

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Accepted 1 May 2006 Clin. Otolaryngol. 2006, 31, 310-316

Objectives: (i) To evaluate head and neck cancer patient perspectives regarding the usefulness of quality of life questionnaires in communicating their health problems to clinicians and (ii) to identify the quality of life questionnaire that head and neck cancer patients find most useful.

Design: Randomised questionnaire study. Patients completed all four validated head and neck cancer quality of life questionnaires – European Organisation for Research and Treatment of Cancer (EORTC), Functional Assessment of Cancer Therapy Scale (FACT) HN35, Washington quality of life questionnaire, Auckland quality of life questionnaire. Order of questionnaire presentation was randomised to counterbalance order effects.

Setting: Tertiary referral head and neck cancer centre. Participants: Eighty patients diagnosed and treated for head and neck cancer. Exclusion criteria: blindness, learning difficulties or inability to understand or read English. Main outcome measures: Patient ratings of perceived usefulness and preferences of studied questionnaires. Results: Patients reported high relevance to their problems and high ease of understanding of all questionnaires, with FACT scoring highest (79% and 89%, respectively); 58% of participants (67% respondents) would like to complete a questionnaire in clinic, as it would help them describe their health problems to their doctors; 28% of participants did not. Almost half preferred a particular quality of life questionnaire, FACT being most preferred. Length of questionnaire did not affect reported usefulness, but most

would prefer a short questionnaire (<20 items).

Conclusions: Patients report that head and neck cancer quality of life questionnaires effectively describe their health concerns. Most are in favour of completing quality of life questionnaires in clinic, as an aid for describing health problems to clinicians. There appears to be a difference between clinicians and patients regarding the perceived usefulness of quality of life questionnaires in the clinic setting, which needs to be highlighted to clinicians.

CANCRO DEL DISTRETTO TESTA-COLLO

Otolaryngology-Head and Neck Surgery (2007) 136, 405-410

ORIGINAL RESEARCH

Quality-of-life impact of participation in a head and neck cancer support group

Kalpesh T. Vakharia, MD, M. Jafer Ali, MD, and Steven J. Wang, MD, San Francisco, CA

> **OBJECTIVE:** To assess if participation by patients in a head and neck cancer support group improves perceived quality of life (QOL).

> STUDY DESIGN AND SETTING: Subjects for this study included 47 patients at a tertiary Veterans Affairs Medical Center who were previously treated for head and neck cancer. This was a quasi-experimental, post-test study comparing the QOL of 24 patients who participated in a head and neck cancer support group with 23 patients who did not participate. The validated University of Michigan Head and Neck Quality of Life (HNQOL) instrument was used to evaluate head and neck cancer-related QOL.

> **RESULTS:** Patients who participated in the head and neck cancer support group exhibited significantly better scores in the domains of eating, emotion, and pain as well as in the global bother and response to treatment questions of the HNQOL instrument compared with those patients who did not participate. Additional subgroup analysis comparing age, type of treatment, and length of time since cancer diagnosis suggests that these variables were less

> CONCLUSIONS: Our findings suggest that patient participation in a head and neck cancer support group is associated with improved QOL.







CEREBROLESIONE

DISABILITY AND REHABILITATION, 2002; VOL. 24, NO. 5, 259-265

Taylor & Francis Charither Classon

Predictors of quality of life following stroke A. E. MACKENZIE* and A. M. CHANG

Department of Nursing, Floor 7 CCV Chung Chi, The Chinese University of Hong Kong, Shatin, NT, Hong Kong

The purpose of this study was to determine the factors explaining the variance in quality of life during the course of rehabilitation following stroke.

- durata del ricovero
- ictus precedenti
- livello di funzionamento
- supporto sociale

CEREBROLESIONE

Acta Neurol Scand 2003: 107: 324–329 Printed in UK. All rights reserved Copyright @ Blackwell Munksgaard 2003

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Quality of life in stroke patients

Jaracz K, Kozubski W. Quality of life in stroke patients. Acta Neurol Scand 2003: 107: 324–329. © Blackwell Munksgaard 2003.

Objectives – To describe global and domain-specific quality of life (QOL) after stroke and to identify the factors that are important for post-stroke QOL. Material and methods – A hospital-based sample of 72 stroke patients was followed up for 6 months after stroke onset. QOL was assessed using the Polish version of the Quality of Life Index. Regression analysis was performed to identify the variables that I predicted QOL. Results – The overall QOL of stroke patients was relatively good, although worse than that of subjects in a compar group. The highest QOL was found in the 'Family' domain, and lowest in the 'Health and functioning' domain. Emotional suppor depression and functional disability were three separate variables

explaining 38% of the variance in QOL. Conclusions – Strengthening of family support, treatment of depression and reduction of physical dependence may be the decisive factors in improving post-stroke QOL. K. Jaracz¹, W. Kozubski²

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Supporto familiare
Tono dell'umore
Livello di funzionamento
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CEREBROLESIONE



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Annals of Physical and Rehabilitation Medicine 54 (2011) 376-390

Original article / Article original

Assessment of quality of life in stroke patients with hemiplegia

Évaluation de la qualité de la vie après un accident vasculaire cérébral

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Abstract

Stroke is a major public health issue. Even though most hemiplegic stroke patients may obtain a good functional outcome, many remain dissatisfied with their lives. Indeed, quality of life and subjective well-being should be taken into account in any assessment of stroke survival. *Objective.* – To assess long-term quality of life in stroke patients (compared with healthy controls) and the corresponding determinants and predictive factors.

Method. – The patient population consisted of 80 of the 217 first-stroke survivors treated between January and June 2005 in the Clinical Neurosciences Department at Bordeaux University Hospital. After a mean follow-up period of 2 years, 24 patients were interviewed in their homes and data from the 56 others were obtained in a telephone interview. Demographic information, clinical status on admission and functional status (as assessed by Barthel Index) and depression (on the ADRS) at the time of the study visit were recorded. Quality of life was assessed by using the Sickness Impact Profile (SIP-65) and Bränholm and Fugl-Meyer's Satisfaction with Life Scale (LiSat 11). The patients' data were compared with those from 149 healthy controls.

Results. - Life satisfaction and quality of life were significantly impaired in stroke patients, compared with controls. All life domains were impaired. The worst scores were observed for independence and health-related items in the LiSat 11 and the physical and communication items in the SIP-65. Quality of life was strongly correlated with functional independence, the persistence of hemiplegia and depressive mood, which is in

agreement with literature findings. Neither gender nor the initial Rankin score had a significant impact on these parameters.

Discussion-Conclusion. - Quality of life at 2 years is significantly impaired in stroke survivors and seems more difficult to predict than functional independence. However, in addition to these objective results, our interviews suggest that receiving adequate social support might be as important to patients as recovering independence.

CEREBROLESIONE

Brain Injury, 20 August 2005; 19(9): 657-665



ORIGINAL PAPER

Self-concept can be defined as a collection of representations reflecting a person's beliefs about his/her own functioning in various life dimensions, such as physical self-concept and social self-concept

Self-concept and quality of life following aquired brain injury: A pilot investigation

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(Received 7 January 2004; accepted 12 July 2004)

greater perceived QoL was associated with a more positive view of self in:

- physical functioning
- social functioning
- functioning within a family

Abstract

Objective: To investigate through pilot exploration the relationships between depression, self-concept and perceived quality of life (QoL) in post-acute patients with acquired brain injury (ABI).

Methods: Nineteen patients with ABI were administered the Beck Depression Inventory-II and the Quality of Life Inventory, along with the Tennessee Self-Concept Scale-2 and the Head Injury Semantic Differential Scale, measures of self-concept. The relationships between these measures were explored using correlational analyses.

Results: Ratings of self-concept were correlated with perceived QoL, suggesting that poorer view of self was associated with lower subjective QoL. Additionally, depressive symptoms were associated with lower QoL ratings, consistent with previous research.

Condusions: These results suggest that intra-personal variables, such as self-concept and depression, impact the perceived QoI of the ABI survivor. Future research exploring the mediating effects of these variables on QoL may clarify this relationship and may aid in developing more effective interventions for these individuals.





CEREBROLESIONE

Brain Injury, June 2005; 19(6): 403-415



ORIGINAL ARTICLE

Female body image following acquired brain injury

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University of Wales, Swansea, Wales, UK

(Received 5 February 2004; accepted 8 November 2004)

Abstract

Primary objective: To investigate body image concerns and psycho-emotional health in females with acquired brain injury (ABI).

Research design: Between subjects design.

Methods and procedures: Thirteen females with ABI and thirteen matched controls were assessed on a number of variables relating to body image, self-esteem and affect.

Main outcomes and results: Indicated that women with ABI had a different profile of body image dissatisfaction than controls and that in some areas it was significantly worse. The women with ABI had significantly lower self-esteem and higher levels

of depression dian controls and dris related to body image.

Conclusion: Significant changes in body image and self-concept are potentially damaging to quality of life post-injury and suggest a role for targeted therapeutic work with women with ABI.

scopo principale del trattamento \rightarrow allineare gli assi visivi in modo da raggiungere un'unica visione binoculare con una buona fusione delle immagini

altri vantaggi:

- miglioramento delle alterazioni posturali del capo
- ampliamento e centralizzazione del campo visivo
- miglioramento della motilità oculare
- miglioramento dello sviluppo psicomotorio
- recupero di un «normale» aspetto fisico

problematiche psicosociali ed emotive tipiche:

- ridotta autostima
- pregiudizio sociale
- bullismo
- incremento dell'ansia sociale
- relazioni interpersonali fragili
- problematiche nel trovare un lavoro

STRABISMO

Quality of life of patients with strabismus

Qualidade de vida em pacientes estrábicos

GERALDO DE BARROS RIBEIRO¹, ANA GABRIELA ZUM BACH¹, CAMILA MAIA FARIA¹, SUZE ANASTÁSIA¹, HENDERSON CELESTINO DE ALMEIDA¹

ABSTRACT

Purpose: To evaluate the impact of strabismus on quality of life.

Methods: This cross-sectional study included 101 individuals aged 7-67 years with strabismus. They were interviewed and made to answer a questionnaire with 20 questions intended to assess the individual's interaction with their social and working environment, sensory perception, and limitations in their daily lives. There were five types of possible responses for each question: never, rarely or very few times, sometimes, frequently, and always. The questionnaire was based on the AS-20 and contained 11 questions assessing psychosocial aspects and 9 questions assessing functional aspects. Among those who were interviewed, 24.8% had undergone surgical correction of strabismus.

Results: We observed a significant impact of strabismus on the quality of life of the interviewed individuals. Feelings of sadness and inferiority because of strabismus were reported by 74.2% and 58.4% respondents, respectively. In terms of functionality, 12.1% reported difficulty in reading, 14% said they had difficulty in depth perception (stereopsis), and 17.8% frequently or always associated pain or burning sensation in the eyes to strabismus. A significant difference was detected in the quality of life scores for the psychosocial aspect among patients who had and had not undergone surgery (Wilcoxon test, 158; p<0.001). Individuals who had

Conclusions: In this evaluation, we found a significant negative interference of strabismus on quality of life from both the functional and psychosocial perspectives. This demonstrated the importance of treatment for strabismus, regardless of age, because it can interfere with the functional well-being of the individual.

RESUMO

Objetivo: Avaliar a interferência do estrabismo na qualidade de vida em indivíduos estrábicos.

Métodos: Estudo transversal envolvendo 101 indivíduos estrábicos entre 7 e 67 anos. Eles foram entrevistados e responderam um questionário com 20 perguntas aplicadas pelos pesquisadores. As perguntas tinham como objetivo avaliar a interação do indivíduo com o seu meio social, de trabalho, percepção sensorial e limitações na sua vida diária, com cinco tipos de respostas para cada pergunta: nunca, raramente ou muito pouco, algumas vezes, frequentemente e sempre. O questionário foi baseado no AS-20 e contendo 11 questões avaliando aspectos psicossociais e 9 questões avaliando aspectos funcionais. Entre os indivíduos entrevistados, 24,8% haviam sido submetidos a correção cirúrgica do estrabismo.

Resultados: Observou-se impacto significativo do estrabismo sobre a qualidade de vida dos indivíduos avaliados. Sentir-se incomodado ou inferiorizado em decorrência do estrabismo foram relatados por 74,2% e 58,4% dos entrevistados respectivamente. No quesito de funcionalidade, 12,1% relataram dificuldade para ler, 14% disseram ter dificuldade na percepção de profundidade (estereopsia) e 17,8% associaram dor ou ardor nos olhos ao estrabismo frequentemente ou sempre. Diferença significativa foi detectada com respeito ao escore de qualidade de vida no aspecto psicossocial entre indivíduos que realizaram e não realizaram cirurgia (teste de Wilcoxon = 158, p-valor <0,001). Indivíduos que realizaram cirurgia possuíam melhor qualidade de vida no aspecto psicossocial.

Conclusões: Nessa avaliação, percebe-se uma interferência negativa muito significativa do estrabismo na qualidade de vida, tanto funcional como psicossocial nos indivíduos pesquisados. Isso demonstra a importância do tratamento do estrabismo, independente da idade, pois ele pode interferir muito na qualidade de vida e bem estar psicossocial e funcional do indivíduo.

Annex. Questionnaire on the impact of strabismus on patient quality of life

Questions	Never	Rarely or very few times	Sometimes	Frequently	Always
1- Do you notice you have strabismus (crossed eyes or lazy eyes)?					
2- Does strabismus bother you?					
3-When you interact with other people, do you feel they notice your strabismus?					
4- Do you feel different (inferior) because of strabismus?					
5- Do you feel that strabismus hinders your performance (at school or at work)?					
6- Do you feel that strabismus affects your relations with other people?					
7-Do you feel that your opportunities (social interaction or at work) are fewer because of strabismus?					
8- Do you imagine what other people are thinking about your eyes?					
9- Do you have more difficulty in making friends because of strabismus?					
10- Do you feel uncomfortable if someone asks something about your eyes?					
11- Do you feel that people avoid looking at you because of strabismus?					
12- Does strabismus hinder your vision?					
13- Do you have difficulty in reading because of strabismus?					
14- Do you feel more stressed out (anxious) because of strabismus?					
15- Do you have difficulty in depth perception (assess the distance of objects)?					
16- Do you feel any discomfort such as pain or burning sensation in the eyes because of strabismus?					
17- Do you have to close one of your eyes to read?					1
18- Do you have diplopia (double vision)?					
19- Do you feel eye strain because of strabismus?					
20- Do you think about your strabismus so frequently that it hinders your concentration?					1

Lo strabismo rappresenta un problema? 49.5% sempre Ti senti inferiore a causa dello strabismo? 41.5% sempre Lo strabismo ti crea dei problemi sul lavoro o a scuola? 22.7% sì Lo strabismo ti ha mai creato problemi nei rapporti interpersonali? 53% sì Le persone evitano di guardarti a causa dello strabismo? 16.8% spesso + sempre

Changes in Health-Related Quality of Life 1 Year Following Strabismus Surgery (Am J Ophthalmol 2012;153: 614–619) SARAH R. HATT, DAVID A. LESKE, LAURA LIEBERMANN, AND JONATHAN M. HOLMES

• PURPOSE: To report changes in health-related quality of life (HRQOL) 1 year following strabismus surgery.

• CONCLUSIONS: Adult strabismus patients who remain successfully aligned show continued improvement in both psychosocial and function scores from 6 weeks to 1 year postoperatively, indicating that improvement in HRQOL is long-lasting. Evaluation of HRQOL should be considered when reporting strabismus surgery outcomes in clinical trials, and may prove helpful in assessing outcomes in clinical practice.

GLAUCOMA

- patologia che colpisce il nervo ottico, che subisce una compressione/schiacciamento a causa dell'incremento della pressione intraoculare
- progressiva alterazione del campo visivo fino alla cecità
- obiettivi: conservare la funzione visiva e la QOL
- la QOL correlata alla funzione visiva è associata all'ampiezza del campo visivo anche in fase precoce; difficoltà nello svolgere attività a distanza, nella guida e nella visione dei colori incidono sulla QOL (Alqudah et al., 2016)

PSICOPATOLOGIA

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Determinants of quality of life in people with severe mental illness

Hansson L. Determinants of quality of life in people with severe mental L. Hansson illness. Acta Psychiatr Scand 2006: 113 (Suppl. 429): 46-50. © 2006 Blackwell Lund University, Lund, Sweden Munksgaard. Objective: The objective of this article was to review some methodological issues in this field and give an overview of empirical research findings with a special focus on factors associated with or affecting subjective quality of life in people with a severe mental illness. Method: A selective review of relevant scientific literature on quality of life in severe mental illness was conducted. Results: Subjective quality of life in people with a severe mental illness is only to a lesser extent related to external life conditions. Major determinants are psychopathology, especially symptoms of depression and anxiety, and aspects of the social network. Personality related factors such as self-esteem are also influential. Comparative studies have further shown that patients in community care settings have a better subjective quality of life than natients in hospital settings Conclusion: Efforts to improve subjective quality of life in people with Lund, Sweden, E-mail: lars.hansson@omv.luse severe mental illness should include a careful monitoring of depressive and anxiety symptoms, and pay particular attention to assessment of and interventions against unmet needs. Further, such interventions should stress a strengthening of the social support of the clients. It is also important to pay attention to mediators of changes in subjective quality of life such as self-esteem, mastery, autonomy, and self-efficacy.

Department of Health Sciences, Division of Nursing

Key words: subjective quality of life; psychopathology; social support; personality; treatment outcome

Lars Hansson, Department of Health Sciences, Division of Nursing, Lund University, PO Box 157, SE-221 00

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