Journal Of Medical Science And Clinical Research
IGM Publication   An Official Publication Of IGM Publication

Original Research Article
Determinants of Illness Perception in Patients with Carcinoma

Authors
Dr Anirban Ray[1*], Dr Anjana Basu[2], Dr Ronti Ghosh[3], Dr Anindya Chakraborty[4], Dr Aalokdut Sarkar[5], Dr Alok Ghosh Dastidar[6]

[1]Associate Professor, Department of Psychiatry, Institute of Post Graduate Education and Research, Kolkata, West Bengal, India
[2]Assistant Professor, R. G. Kar Medical College & Hospital
[3]Junior resident, Department of Radiotherapy, Institute of Post Graduate Education and Research
Currently: Radiation Oncologist, AMRI Hospitals
[4]Assistant Professor, Department of Radiotherapy, College of Medicine & Sagar Dutta Hospital
Deputed at: Institute of Post Graduate Education and Research
[5]Junior Resident, Department of Radiotherapy, Institute of Post Graduate Education and Research
[6]Professor, Department of Radiotherapy, Institute of Post Graduate Education and Research
*Corresponding Author
Dr Anirban Ray
Associate Professor, Department of Psychiatry, Institute of Post Graduate Education and Research, Kolkata, West Bengal, India

Abstract
Introduction: *People try to explain their diseases through their own existing schema. That leads to different perceptions of the diseased state among them. That, in turn, leads to different coping strategies & different psychological consequences.*
Materials & Methods: *An open domain instrument, B-IPQ (Brief Illness Perception Questionnaire) was translated in the Bengali language. 198 diagnosed carcinoma patients were recruited from radiotherapy OPD for the study. Measured illness perception is analyzed for dependence on different demographic & disease parameters.*
Results: *Translated instrument had a good internal consistency (α =0.82). TNM stage of the disease ($p = 0.004$) or education of the patient ($p = 0.008$), marital status ($p= 0.015$) and psycho-education status ($p = 0.001$) predict the illness perception.*
Discussion & Conclusion: *Less educated & widowed or divorced persons perceive the disease more threatening. Retired persons seem to have more severe perceptions about the disease. Proper Knowledge of the disease has a role in allaying fear about the disease. Psycho-education along with supportive therapy can be very effective in this patient group. Further interventional study of the effectiveness of such modules can be undertaken in future.*
Keywords: *Illness perception, carcinoma, determinants, psycho-education.*

Introduction

From the onset of civilization, the human has tried to explain all the incidents around him or within him by their own intellect through forming different models that seem logical to them. They react to those incidents based on the schema they have for those incidents. Human illness behaviors are no different. Illnesses are stressful to any human beings as it's a deviation from normalcy. So they try to explain their diseases by their past experiences and cultural beliefs. They attribute different probable causalities for the diseases and use different coping strategies to deal with them. Leventhal & colleagues proposed a model that is widely known as Self-Regulation Theory & Common Sense Model of illness representation.[1,2] It provided a framework of understanding of how an individual person experience symptoms and emotions during a health threat. It explained, how a particular diagnosis influences the perception of illness for an individual and how their own personal beliefs determine how they respond and cope with threats to health. The concept of illness perception in patients stemmed from this concept[2,3]. Illness perception questionnaire (IPQ) was developed to measure this construct.[4] It was further modified to improve the psychometric property to develop a Revised Illness Perception Questionnaire (IPQ-R) to cover 5 domains of perceptions, which are causality, identity, timeline, cure-control, consequences[5]. Broadbent et. al. reduced the scale to a 9 item short & fast assessment of cognitive & emotional representation of the illness called Brief IPQ[6]. This open domain tool has been translated to many languages to facilitate catching the cognitive representation of the patients even the healthy adults[7] in those languages[8-9] and also adapted for different diseases both acute[10] & chronic[11,12]. Illness perception has also been proven to modify the psychological well-being, social functioning, coping strategies, vitality, and disease outcome. [13]

Carcinoma is a dreaded name from time immemorial. Though with the striking improvement of therapeutics, life expectancy has improved, still good responses are more exceptions than the rule. Carcinomas have considerable therapeutic side effects that reduce the quality of life. These factors induce stress in patients that can result in psychological morbidity in the patients. Illness perception of the patient & family can have a significant impact on the illness behavior of the patient, psychological wellbeing & quality of life of the patients. There are several studies throughout the world addressing this area [8,14-19]. Illness perception varies in different societies according to the belief systems; hence, this questionnaire (B-IPQ) has been translated in different languages and used in different societies [9,20-23]. To best of our knowledge, no study to date targeted Bengali population for assessment of illness perception in cancer patients with a translated Bengali version of Brief-IPQ. Very few studies tried to explore demographic & clinical determinants of the B-IPQ measures [24]. This study aims to find out the determinants of illness perception in patients with carcinoma in a tertiary care hospital of eastern India.

Methods

Bengali translation of Brief-IPQ (generic form) had been used to assess the beliefs and emotional representations about the illness. This nine-item questionnaire is an open domain questionnaire available from http://www.uib.no/ipq/. First eight items are numerical items and 9th is acausal item which enumerates top three speculations of causality. Each item of the Brief IPQ assesses one dimension of illness perception. Each item to be rated in a scale of 0-10. To compute the overall score, item number 3, 4 and 7 are reversed and added with the sum of items 1,2,5,6 and 8 to get the total 'illness perception score'(IPS) which represent 'overall threat perception' regarding the illness under consideration.

Three translation processes were employed to translate the questionnaire (B-IPQ) to Bengali.

Forward translation, committee translation, and back translation, along with patient testing [25]. The last phase was done through this work.

First, three translators (bilingual to English & Bengali) translated the original English version to Bengali version. Then two experts of the subject who had the experience to work with Bengali patients reviewed all the translations to reach a final approved Bengali form. After that, again one bilingual translator, who was not acquainted with the English form, translated back the final Bengali translation to English. After that one English language- expert was consulted to determine the comparability of two English versions. Then the final Bengali versions of the questionnaire were finalized. The final patient testing part was done during course of this study.

This interview-basedcross-sectional and observational study had been done in oncology and radiotherapy outpatient department (OPD) of a tertiary care canter of West Bengal, India. Consecutive patients coming to the OPD, who can read or write the Bengali language were approached for enrolment in the study. Those who gave informed consent were given preliminary data questionnaire along with B-IPQ. Post graduate trainees of department of radiotherapy applied these questionnaire, who were trained by consultant psychiatrist regarding procedure of administration of these questionnaires. Some clinical information was filled in by treating team according to patient's treatment file. Altogether 198 diagnosed carcinoma patients were recruited for the study.

Result & Analysis

Analysis reveals eight-item numerical scale, except the causal items to have good internal consistency (Cronbach's α 0.82) and inter-item correlation 0.36 but coherence item (no 7), which is a reverse score item, had poor correlation with other items, and dropping that item marginally increases the Cronbach's α (0.867). But as here all the items measure separate areas of disease perception, and the scale has good internal consistency as such, item 7 was kept for further analysis.

Analysis using first eight numerical items of the scale revealed, illness perceptions were not significantly associated with on family income, age, sex, religion (Hindu or Muslim) treatment modality chosen (radiotherapy, chemotherapy or combined), histological (adenocarcinoma, squamous cell carcinoma & others) diagnosis of carcinoma, duration of the disease (<6mn or more) and residential status (urban & rural) of the patients, diagnoses of carcinoma (according to the organ involved i.e. Genitourinary, Lung, Breast, Head Neck, Gastrointestinal tract and others). Occupation of the patient (eg. unemployed, retired, housewife (females), self-employed or service-holder) (Table 1).

On the other hand (Table 1) TNM staging of the cancer significantly impacted overall threat perception score (p=0.004).Post hoc test (Least Significant Difference) showed, severity of illness perception increases with increase stage of the disease. Stage 1 has significantly less severe illness perception from Stages 3 (p =0.039) & 4 (p = 0.004). Stage 2 has significantly different from stage 4 (p=0.002) only. Illness perception severities in other disease stages are not significantly different mutually. Education of the patient also had a significant impact on total illness perception score (IPS) (p= 0.008). Post hoc test (Least Significant Difference) persons with education only up to 'Primary' has significantly more severe illness perception than person's with education up to secondary (p=0.019), undergraduate (p= 0.028), graduate and above (p=0.009). Other groups don't have significant difference among them in this regard. Overall threat perception (IPS) also significantly dependant on marital status (p=0.015) (married, single, single-again (divorced and widowed)). Post hoc test (Least Significant Difference) showed that 'married' persons have significantly less severe illness perceptions from 'single again' (p= 0.004) group. 'Single' group itself is not significantly differ in illness perception than both

'married' and 'single again' groups. Psycho-education comprises of clear knowledge of the diagnosis, likely management lines & prognosis. Level of psycho-education was assessed by interview technique in this study. We included all patient irrespective of whether their psycho education was complete or not. However respective treating team was informed about the status, and pursued so that psycho-education is completed by them. Status of psycho-education was also an important determinant for illness perception. Those who were fully psycho-educated, had less total threat perception (IPS mean difference -6.899, p=0.001) than those who had lacuna in their psycho-education.

Regarding causes, after assessment of themes initially, eight themes for causes were identified (Alcohol, anxiety, can't say, wrong treatment or chronic problem, excessive workload, irregular nutrition, smoking, childbirth, lactation, smoking & tobacco). But as some of the causes have very low frequency; these causes were condensed into 5 main themes (can't say, addiction, environment, and nutrition, feminine causes, others). When 1st response only was considered, interestingly most of the patients (54%) (Fig – 1) couldn't say the cause of illnesses. Addiction is the most frequent putative reason (30.3%) that came first in their minds, followed serially in frequency by external factors like irregular food and nutrition or pollution (7.1%), marriage, childbirth and lactation (2.5%) and other factors like anxiety, wrong treatment, excessive workload, and chronic illness (6.1%). For the sake of better assessment of considering all three responses of causality 'can't say' was still the most frequent response (46.1%) (Fig-2).

Table-1: Determinants of illness perception severity

		Mean ± SD	Significance (p- Value)	
Age	n=198	50.54 ± 12.882	r = 0.110, p=0.123	Pearson's Correlation
Income	n=198	3662.35 ± 5074.858	r = 0.015, p=0.832	Pearson's Correlation
Sex	Male (n=107)	42.05 ± 14.819	p= 0.680	
	Female (n= 91)	42.92 ± 14.959		
Religion	Hindu (p= 163)	41.75 ± 15.063	p = 0.152	
	Muslim (p= 35)	45.71 ± 13.551		
Psycho-education	Complete (p= 109)	39.35 ± 13.813	**p = 0.001**	
	Not complete(n=89)	46.25 ±15.269		
Residence	Urban (n=46)	40.98 ± 15.207	P = 0.445	
	Rural (n=152)	42.89 ± 14.765		
Marital Status	Married (n=158)	41.13 ± 14.714	**p = 0.015** (ANOVA)	
	Single (n=18)	43.78 ± 14.799		
	Single Again (n=22)	50.82 ± 13.616		
Duration	<6 month (N=150)	41.60 ± 15.006	P = 0.155	
	>6 month (N=48)	45.10 ± 14.186		
Occupation	Unemployed (n=17)	40.35 ± 11.516	p = 0.323 (ANOVA)	
	Retired (n=11)	38.45 ± 15.731		
	House wives (n=74)	42.20 ± 15.384		
	Self-employed (n=58)	45.62 ± 15.160		
	Service (Govt + Private) (n=38)	40.18 ± 14.190		
Diagnosis of Carcinoma	Genitourinary(n=39)	38.33 ± 16.631	p = 0.070	
	Lung (n=33)	44.88 ± 14.622		
	Breast n=29)	37.79 ± 13.574		
	Head & Neck(n=30)	44.77 ± 11.619		
	GI tract (n=44)	46.07 ± 14.850		
	Others (n=23)	41.87 ± 15.546		
Histological	Adeno-Carcinoma (n=105)	15.790 ± 1.541	P = 0.171	

| Diagnosis	Squamous Cell Carcinoma (n=68)	13.010 ± 1.578		
	Others (n=25)	15.026 ± 3.005		
Treatment Modality	Radio (n=9)	45.56 ± 14.570	p = 0.204	
	Chemo (n=37)	45.95 ± 14.520		
	Combined (n=152)	41.41 ± 14.887		
Level of Education	Primary (n=101)	45.79 ± 14.677	**p = 0.008 (ANOVA)**	
	Secondary (n=61)	40.25 ± 14.714		
	Under Graduate (n=18)	37.56 ± 11.137		
	Graduate & Above (n=18)	36.06 ± 15.761		
TNM Stages	Stage 1 (n=10)	33.90 ± 12.279	**P =0.004 (ANOVA)**	
	Stage 2 (n=83)	39.67 ± 15.259		
	Stage 3 (n=76)	44.00 ± 13.501		
	Stage 4 (n=29)	49.28 ± 15.156		
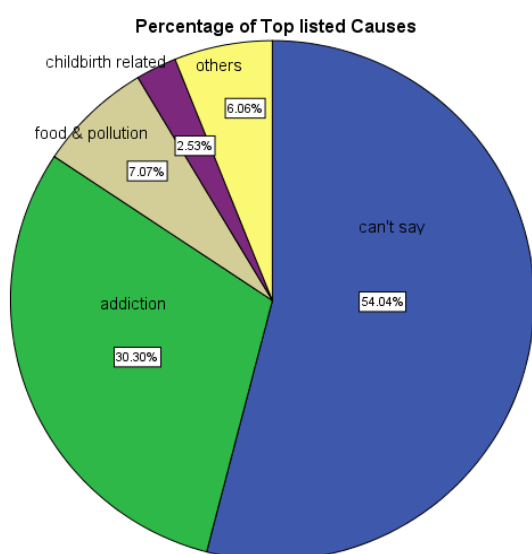
Fig 1: First mentioned cause percentage
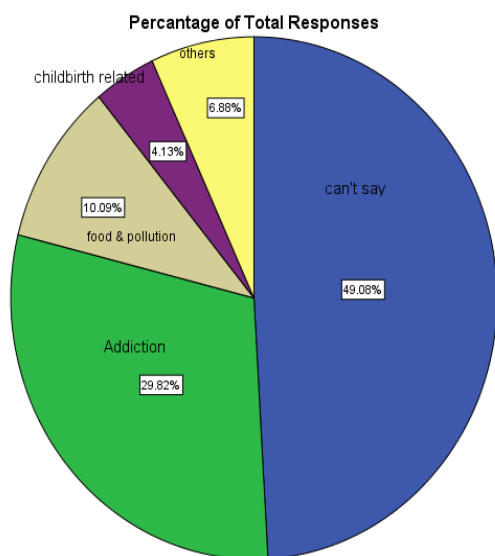
Fig 2 Total Causal response percentage

Discussion

Many studies have proven that, illness perception has significant role in treatment adherence [26, 27].

Rarely any study tried to look into the socio-demographic variables as determinants for illness perception. One study has found no correlations between them[28]. But in this study, we have found some clear trends in a case on carcinoma patients in general. These may be clinically significant, especially during planning psycho-education for such patients.

Interestingly, according to this study, family income, residential status (rural or urban), even the disease duration does not have an impact on the cognitive representation of the disease, but education has an impact. Those who do not have secondary education, have a significantly more negative view of their disease. Among those having secondary education or higher, if education is more, then perception about their disease is better, with less overall threat perception. This is in consonance of other studies which also shown if the education is positively correlated with illness perception[29]. Here at least secondary level education seemed to be beneficial for patients as they may have a less catastrophic illness perception.

Persons who were widowed or divorced seemed to have significantly more threat perception. It is in line with the Quebec Health Survey data, which showed single females have more negative perception of their general health[30].

In line of few other studies[31,32], this study also shown that illness perception is dependent on disease severity. Persons with advanced stage of disease, have more negative illness perception.

This study showed, those who had full knowledge about their carcinoma diagnosis, perceived their disease significantly less dreaded. This is supported by a recent study indirectly which showed in a real world study, a group psycho-education program in patients with bipolar disorder, multiple benefits resulted including improvement in illness perception, medication adherence, knowledge of the disease along with final improvements in social functioning and self-esteem. This improvement in functioning is mediated by improvement in illness perception only, rather than treatment adherence or knowledge[33]. Hence it is necessary to properly psycho-educate every carcinoma patient.

Regarding perceived causation, it seemed from study result that popular notions of causalities of common carcinomas were approximately appropriate. The study showed addiction and smoking as a cause of lung carcinoma or early marriage as a cause of genitourinary carcinomas. But most of the people also have no clue about their disease causation. Some people also had some wrong & dysfunctional belief, which needs to be corrected through proper Psycho-education.

Study with a larger sample size can add more value to the results as this has dealt with alarge number of determining variables for illness perception. But this study is unique as it has explored the determinants of illness perceptions in general and identify areas of future research. Future studies with pre-post design with psycho-education as the intervention strategy can prove the point more comprehensively.

Conclusion

This study emphasized the need for proper psychoeducation in carcinoma patients. Clear communication and disclosure of the fact could be beneficial for patients. Poorly educated, divorced or widowed patients were at risk group with poor illness perceptions, who needs more psychoeducation and psychological support. Further studies with larger sample size would be needed in future. Based on further qualitative work with these patients some treatment module can be devised. And with further study of changes in illness perception with that treatment module can be assessed to validate the treatment module.

References

1. Browning KK, Wewers ME, Ferketich AK, Otterson GA, Reynolds NR. The Self-regulation Model of Illness applied to smoking behavior in lung cancer. Cancer Nurs. 2009 Aug;32(4): E15–25.
2. Hale ED, Treharne GJ, Kitas GD. The Common-Sense Model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? Rheumatology. 2007 Jun 1;46(6):904–6.
3. Weinman J. T 7 ILLNESS PERCEPTIONS: A New Paradigm. Health Psychol Read. 2002;250.
4. Weinman J, Petrie KJ, Moss-Morris R, Horne R. The illness perception questionnaire: a new method for assessing the cognitive representation of illness. Psychol Health. 1996;11(3):431–45.
5. Moss-Morris R, Weinman J, Petrie K, Horne R, Cameron L, Buick D. The Revised Illness Perception Questionnaire (IPQ-R). Psychol Health. 2002 Jan;17(1):1–16.
6. Broadbent E, Petrie KJ, Main J, Weinman J. The Brief Illness Perception Questionnaire. J Psychosom Res. 2006 Jun;60(6):631–7.
7. Figueiras MJ, Alves NC. Lay perceptions of serious illnesses: An adapted version of the Revised Illness Perception Questionnaire (IPQ-R) for healthy people. Psychol Health. 2007 Feb;22(2):143–58.

8. Giannousi Z, Manaras I, Georgoulias V, Samonis G. Illness perceptions in Greek patients with cancer: a validation of the Revised-Illness Perception Questionnaire. Psychooncology. 2010 Jan;19(1):85–92.

9. Broadbent E, Kaptein AA, Petrie KJ. Double Dutch: The "think-aloud" Brief IPQ study uses a Dutch translation with confusing wording and the wrong instructions: Double Dutch. Br J Health Psychol. 2011 May;16(2):246–9.

10. Petrie KJ, Weinman J, Sharpe N, Buckley J. Role of patients' view of their illness in predicting a return to work and functioning after myocardial infarction: a longitudinal study. BMJ. 1996;312(7040):1191–4.

11. Van der Have M, Minderhoud IM, Kaptein AA, Leenders M, Siersema PD, Fidder HH, et al. Substantial impact of illness perceptions on quality of life in patients with Crohn's disease. J Crohns Colitis. 2013 Sep 1;7(8):e292–301.

12. Tiemensma J, Kaptein AA, Pereira AM, Smit JWA, Romijn JA, Biermasz NR. Negative illness perceptions are associated with impaired quality of life in patients after long-term remission of Cushing's syndrome. Eur J EndocrinolEur Fed Endocr Soc. 2011 Oct;165(4):527–35.

13. Hagger MS, Orbell S. A Meta-Analytic Review of the Common-Sense Model of Illness Representations. Psychol Health. 2003;18(2):141–84.

14. Anagnostopoulos F, Spanea E. Assessing illness representations of breast cancer: a comparison of patients with healthy and benign controls. J Psychosom Res. 2005 Apr;58(4):327–34.

15. Gould RV, Brown SL, Bramwell R. Psychological adjustment to gynecological cancer: patients' illness representations, coping strategies and mood disturbance. Psychol Health. 2010 Jun;25(5):633–46.

16. Hoogerwerf MA, Ninaber MK, Willems LNA, Kaptein AA. "Feelings are facts": Illness perceptions in patients with lung cancer. Respir Med. 2012 Aug;106(8):1170–6.

17. Husson O, Thong MSY, Mols F, Smilde TJ, Creemers G-J, van de Poll-Franse LV. Information provision and patient-reported outcomes in patients with metastasized colorectal cancer: results from the PROFILES registry. J Palliat Med. 2013 Mar;16(3):281–8.

18. Millar K, Purushotham AD, McLatchie E, George WD, Murray GD. A 1-year prospective study of individual variation in distress, and illness perceptions, after treatment for breast cancer. J Psychosom Res. 2005 Apr;58(4):335–42.

19. Mols F, Denollet J, Kaptein AA, Reemst PHM, Thong MSY. The association between Type D personality and illness perceptions in colorectal cancer survivors: a study from the population-based PROFILES registry. J Psychosom Res. 2012 Sep;73(3):232–9.

20. Brzoska P, Yilmaz-Aslan Y, Sultanoglu E, Sultanoglu B, Razum O. The factor structure of the Turkish version of the Revised Illness Perception Questionnaire (IPQ-R) in patients with diabetes and cardiovascular disease. BMC Public Health. 2012 Oct 9;12(1):852.

21. Norfazilah A, Samuel A, Law PT, Ainaa A, Nurul A, Syahnaz MH, et al. Illness perception among hypertensive patients in primary care center UKMMC. Malays Fam Physician [Internet]. 2013 [cited 2014 Apr 18];8(3). Available from: http://www.e-mfp.org/2013v8n3/illness-perception-hypertension.pdf

22. Sjölander M, Eriksson M, Glader E-L. The association between patients' beliefs about medicines and adherence to drug treatment after stroke: a cross-sectional questionnaire survey. BMJ Open. 2013 Sep 1;3(9):e003551.

23. Steca P, Greco A, Monzani D, Politi A, Gestra R, Ferrari G, et al. How does illness severity influence depression, health satisfaction and life satisfaction in patients with cardiovascular disease? The mediating role of illness perception and self-efficacy beliefs. Psychol Health. 2013 Jul;28(7):765–83.

24. Giusti M, Melle G, Fenocchio M, Mortara L, Cecoli F, Caorsi V, et al. Five-year longitudinal evaluation of quality of life in a cohort of patients with differentiated thyroid carcinoma. J Zhejiang UnivSci B. 2011 Mar;12(3):163–73.

25. Gausia K, Hamadani JD, Islam MM, Ali M, Algin S, Yunus M, et al. Bangla translation, adaptation and piloting of Edinburgh Postnatal Depression Scale. Bangladesh Med Res Counc Bull. 2007;33(3):81–7.

26. Mosleh SM, Almalik MM. Illness perception and adherence to healthy behaviour in Jordanian coronary heart disease patients. Eur J CardiovascNurs. 2016 Jun;15(4):223–30.

27. Cooper A, Lloyd G, Weinman J, Jackson G. Why patients do not attend cardiac rehabilitation: role of intentions and illness beliefs. Heart. 1999 Aug 1;82(2):234–6.

28. Shabahang H, Panahi G, Noferesti G, Sahebghalam H, Robubiat S, Bolurian M. Illness perception of breast cancer in affected women undergoing chemotherapy. Med J Islam Repub Iran MJIRI. 2011;25(2):76–81.

29. Hirsch D, Ginat M, Levy S, Benbassat C, Weinstein R, Tsvetov G, Singer J, Shraga-Slutzky I, Grozinski-Glasberg S, Mansiterski Y, Shimon I. Illness perception in patients with differentiated epithelial cell thyroid cancer. Thyroid. 2009 May 1;19(5):459-65.

30. Soubhi H, Fortin M, Hudon C. Perceived conflict in the couple and chronic illness management: Preliminary analyses from the Quebec Health Survey. BMC FamPract [Internet]. 2006 Dec [cited 2018 Oct 6];7(1). Available from: http://bmcfampract.biomedcentral.com/articles/10.1186/1471-2296-7-59

31. Majoor BCJ, Andela CD, Quispel CR, Rotman M, Dijkstra PDS, Hamdy NAT, et al. Illness Perceptions are Associated with Quality of Life in Patients with Fibrous Dysplasia. Calcif Tissue Int. 2018 Jan;102(1):23–31.

32. Porkert S, Lehner-Baumgartner E, Valencak J, Knobler R, Riedl E, Jonak C. Patients' Illness Perception as a Tool to Improve Individual Disease Management in Primary Cutaneous Lymphomas. ActaDermVenereol. 2018;98(2):240–5.

33. Etain B, Scott J, Cochet B, Bellivier F, Boudebesse C, Drancourt N, et al. A study of the real-world effectiveness of group psychoeducation for bipolar disorders: Is change in illness perception a key mediator of benefit? J Affect Disord. 2018;227:713–20.