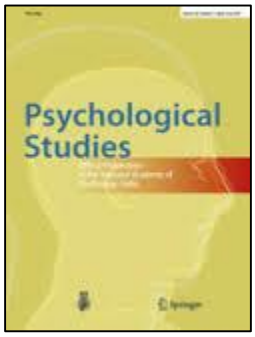

Test Construction of Caregiver Collusion Questionnaire

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Abstract

A scale to measure the collusion of the diagnosis among caregiver's of terminally ill patients was developed and its psychometric properties were determined. The results showed the measures effectiveness. The measure can be modified for assessing collusion in other settings.

Keywords: Cancer, Caregiver, Collusion, Terminally ill.

Introduction

Research has shown differences in informational needs which depend on attitudes and perceptions of physicians, caregivers and cancer patients (Clayton, Butow & Tattersall, 2005). These needs reflect concerns about the diagnosis, prognosis and treatment (Giacalone, et al. 2009), which varies based on age, gender or cancer stage (Mack, Wolfe, Grier, Cleary, & Weeks,

2006). The physicians want to establish therapeutic alliance, but wait until the patient inquires (Arbabi, et al. 2010). Collusion blocks patient's autonomy and right to information (Ho, Krishna, Goh, & Yee, 2013; Krishna, 2012), and is not the patient's best interest in African, Asian, and Middle East countries (Khalil, 2013).

Chaturvedi, Chandra and Sinha (2008) found that collusion implies to the information (about diagnosis, prognosis and medical details) being withheld by someone and not shared with other significant people. Twycross (2003) states that collusion is a conspiracy of silence or a source of tension, which interferes with communication and interpersonal relationships and blocks discussion of the future and preparation for parting (Milberg & Strang, 2011; Tsai, 2007). If unresolved, the bereaved experiences regret too. The Compact Oxford Dictionary defines collusion as a secret cooperation in order to cheat or deceive.

In India the doctor colludes with the relatives in majority cases (Anne-Mei, Hak, Koeter, & Van der Wal, 2000; Chaturvedi, Loiselle, & Chandra, 2009; Twycross, 2003). Twycross (2003) stated that cancer always changes family psychodynamics, either for better or for worse. Within families, there is a constant conflict between the wish to confide by sharing the information, to receive emotional and/or practical support (Milberg & Strang, 2011) along with a wish to protect the loved ones, from the psychological distress that the information would cause (Back, et al. 2008; Khalil, 2013; Twycross, 2003). In addition, the caregivers often have different opinions (Tsai, 2007). It is felt that relatives in denial withhold the truth (Twycross, 2003).

Zhang, Gary, and Zhu (2012) found that depression and functional decline were closely related to the initial diagnosis of cancer among African-American patients, irrespective of whether the depression is diagnosed before or after the diagnosis of cancer. Cancer patients usually like to know their diagnosis (Tsai, 2007). However caregivers were unwilling to let patients know the truth (Tsai, 2007; Khalil, 2013).

Purakkal, Pulassery, and Ravindran (2004) interviewed pre-clinical students, clinical students, interns, postgraduate registrars and faculty and found that majority stated that the diagnosis should be revealed to patients and wanted to know their diagnosis if they were developing a life threatening illness. The experienced physicians found it better to share the information in an Iranian study (Arbabi, et al. 2010). Weiner and Cole (2004) found that medical professionals had improved skills after a communication training program for shared decision making along a life-limiting illness. This program could be effective for patients, health care providers, and families too. Breaking collusion needs to be done regarding the feelings of patients and relatives and by supporting relatives and patients, when actual facts are shared (Reich, Gaudron & Penel, 2009; Chaturvedi, et al. 2009).

Collusion was operationally defined as the non-disclosure, wrong disclosure or partial disclosure of the diagnosis of a disease, either to the patient and/or to important others like caregivers, etc. in an attempt to protect the individual, who it is hidden from, causing a disturbance in their routine functioning and interpersonal relationships, among the ones who try to protect the other. Therefore a need for developing a questionnaire to measure caregiver collusion about diagnosis was felt.

Method and Results

The caregiver's informed consent was obtained. The data was kept confidential and used only for academic purposes. This questionnaire was approved by the hospice secretary before data collection.

A. Item Generation:-

Based on literature review, 45 statements were framed (Arbabi, et al. 2010; Back, et al. 2008; Chaturvedi, et al. 2008; Helft, Hlubocky, Wen, Ratain, and Daugherty, 2003; Ho, et al. 2013; Mangan, Taylor, Yabroff, Fleming, and Ingham, 2003; Purakkal, et al. 2004; Tsai, 2007; Twycross, 2003; Weiner & Cole, 2004).

B. Content Validation:-

After scrutiny, four items were removed .The 41 item questionnaire was then given to 5 judges (a doctor, a nurse, a psychologist, a social worker and a priest, who have been working in a hospice or a hospital with cancer patients and their caregivers) for content validation. Each item was marked for its relevance, clarity and need for modification. For clarity of the collusion being measured items regarding prognosis were deleted. To the retained 31 items, six items were revised and included based on the jury's suggestion.

C. Item Analysis:-

Then the 37 items were given to 7 caregivers of terminally ill patients. These caregivers included three wives, three mothers and one son. They answered the questionnaire first, then they reviewed each item for its relevance, clarity and need for modification.

An item analysis was done by point-biserial correlation, since the response format was dichotomous and items with a correlation of 0.2 and above were retained. This resulted in a total of 20 items of which 17 items ($p< 0.05$).

D. Reliability:-

These 20 items were administered to 30 caregivers (20 females, 10 males) whose age ranged from 18 to 60. The caregivers included seven wives, three husbands, eight mothers, one father, four sons, three daughters, two brothers and two sisters. The sample's mean was 14.8 and standard deviation was 3.34. The lowest score obtained was six and the highest score was 20.

The Rational equivalence method given by Kuder Richardson was used to find the internal consistency of the questionnaire. The reliability was estimated at 0.74, $p < 0.01$.

Conclusion

The results show that the questionnaire can be used to measure collusion about the diagnosis in caregivers of terminally ill patients. Based on which the reason can be explored and counselling to break collusion can be given, which will help in improving communication and interpersonal

relationship between the patient and caregiver, which in turn will improve the patient's quality of life.

Implication

Slight modifications can help in measuring the caregiver's collusion about prognosis and for finding the collusion among caregivers of patients with curative diseases or chronic illnesses.

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Appendix-

Caregiver Collusion Questionnaire

Instructions :-

"A set of questions related to your feelings and attitudes as a caregiver are given. Read and answer them with a yes / no. There is no right or wrong answers."

1. Are you anxious about your patient due to his / her previous negative reaction to a stressful situation?
2. Is your patient anxiety prone by nature?
3. Are you anxious about your patient's ability to accept his/her condition?

4. Do you think the patient's diagnosis must be shared with the patient ?
5. Do you avoid answering the patient, when the patient asks questions about his/her condition?
6. Are you afraid of revealing the truth to the patient, when you try to handle the patient's complaints?
7. Have you of late been sleeping well?
8. Are you apprehensive about your patient's loss of hope to live, on knowing his / her diagnosis?
9. Have you of late not been inquisitive about what your patient communicates with others?
10. Are you feeling guilty for not disclosing the diagnosis to your patient?
11. Do you think the patient's health will remain stable by keeping the diagnosis a secret?
12. Have you and your doctor agreed to keep the diagnosis a secret, from the patient?
13. Do you think your patient can handle a stressful situation?
14. Do you try to stop the patient from discussing the condition with others?
15. Do you now communicate less than before the patient's condition was known?
16. Has your health been effected by keeping the patient's condition a secret?
17. Do you think your patient will feel disappointed if he/she comes to know the diagnosis from others?
18. Do you think keeping the diagnosis a secret will not create a conflict in the family?
19. Do you think your patient should be allowed to express his/her views regarding how his/her life should come to an end?
20. Do you and the doctor discuss the patient's diagnosis in his/her presence, during consultation?

Scoring:-

Reverse scoring was done for items 4, 7, 9, 10, 13, 19 and 20 and the rest were directly scored. The maximum and minimum possible scores are 20 (high collusion) and zero (no collusion) respectively.